THREE STUDIES OF THE COMMUNICATION ECOLOGY OF ADVANCE CARE PLANNING

A Dissertation

by

JENNIFER JEANENE FREYTAG

Submitted to the Office of Graduate and Professional Studies of
Texas A&M University
in partial fulfillment of the requirements for the degree of

DOCTOR OF PHILOSOPHY

Chair of Committee,	Richard L. Street, Jr.
Committee Members,	Emily Rauscher
	Laura Dague
	Kirby Goidel
Head of Department,	J. Kevin Barge

May 2018

Major Subject: Communication

ABSTRACT

Using an ecological perspective, this dissertation focuses on personal and communicative factors affecting advance care planning. It situates and studies the process of advance care planning within three different contexts: an individual, cognitive context, the familial context, and the clinical context. Study One focused on beliefs and attitudes toward advance care planning using a survey that was completed by patients and their family member healthcare surrogates. The study found differing degrees of concordance for different measures of advance care planning preferences. Concordance ran from fair to good for measures of patient priorities and attitudes toward advance care planning, while concordance was low for decision-making preferences and goals. The study also found that patient perceptions of surrogate openness to talking about death predicts concordance across all but one measure. This finding provides a basis for arguing that interventions targeted exclusively at patients should also focus on surrogates. The study finally connects family communication environment types to concordance scores. Pluralistic family types, which value open communication and free thinking, are associated with improved concordance across two measures.

Study Two uses a qualitative approach to focus on the way family communication environment types can be used to classify family attitudes toward advance care planning conversation and decision-making. The analysis identifies important characteristics of these family communication environments that coordinate with the way patients and surrogates frame the problem of advance care planning, the way they discuss it, and the way they approach decision making in this context. Finally, Study Three uses a mixed-methods approach to analyze secondary data from patient-clinician interactions in a clinical setting, focusing on discursive

strategies physicians and patients use during conversation about end-of-life care and decision-making strategies. It highlights a gulf between patients and physicians in terms of the advance care planning content they become more engaged in discussing. Based on ratings from outside observers, the study found that patients are more engaged when talking about surrogate decision-makers in detail, while physicians are more engaged when talking about advance care planning documents.

DEDICATION

This project is dedicated to C and G, my family. Please accept these pages as evidence of how our family's love and support has provided me with the sustenance to do something that was so difficult but so inspiring. Please also accept these pages as part of a solemn promise that after all these years, I am finally done with graduate school forever.

ACKNOWLEDGMENTS

One of the most important lessons I learned in completing this project is how much I rely on the mentorship and support of so many different people who have been generous with their time and attention.

Key among those people is Dr. Richard Street, Jr., my advisor. I have teased Dr. Street in the past, calling him "Yoda" in part because of his ability to offer well worded pearls of wisdom when I seem to need them most. But the name fits because Dr. Street is the embodiment of the kind of wise mentor every trainee should have: incredibly generous, endlessly patient, relentlessly optimistic, honest, kind, and protecting. I am very lucky to have had the honor of being his advisee, and I hope that I can someday help my own advisees find their path in the same way he has helped me find mine.

Also crucial has been Dr. Emily Rauscher. Dr. Rauscher has been the kind of one-in-a-million teacher who has taught me the work of research by spending hours of her valuable time showing me the craft: sketching out ideas, running statistical models, and poring over manuscripts to make sure the language is right. She has taught me to approach the messy process that leads to academic discovery by seeking precision in my work, which is ultimately what makes research so satisfying. I could not have found such excitement and real joy in the research process without her.

I am also grateful to Dr. Laura Dague and Dr. Kirby Goidel for their invaluable help and feedback throughout this project. I am especially thankful to Dr. Dague for teaching me to think like a policy maker and to truly appreciate the "mother of all social sciences." And I am grateful to Dr. Goidel for making the fundamentals of quantitative research clear and approachable.

I am thankful to have been in the Ph.D. program at the same time as Grace, Paige, Gemmë, Kellie, Arti, and Brittany (a.k.a. the Health Squad). Their excellent humor, easy willingness to listen, and fantastic feedback made this experience meaningful, even when finishing seemed nearly impossible. It has been a privilege to be their peer, and it is even more exciting to know that we will continue to support one another as colleagues.

Finally, I want to thank all of the participants in this project. These people took the time to talk about sometimes difficult issues and to answer hard questions. Their participation is the lifeblood of work like mine. I am grateful for their time and their candor.

CONTRIBUTORS AND FUNDING SOURCES

Contributors

This work was supported by a dissertation committee consisting of Professor Richard L. Street, Jr. (advisor), Professor Emily Rauscher, and Professor Kirby Goidel of the Department of Communication, as well as Professor Laura Dague of the Department of Public Service and Administration at the Bush School of Government & Public Service.

The data analyzed for Chapter V was provided by Professor Rebecca Sudore of the University of San Francisco. Professor Richard L. Street, Jr. is a contributor to the project.

All other work conducted for the dissertation was completed by the student independently.

Funding Sources

There are no outside funding contributions to acknowledge related to the research and compilation of this document.

TABLE OF CONTENTS

LIST OF FIGURES

Page

LIST OF TABLES

Page

CHAPTER I

INTRODUCTION AND OVERVIEW

According to the Dartmouth Atlas of Healthcare (2012), most Americans with chronic diseases report that in the terminal phase of their illness, they want to avoid intensive, invasive care. Of the patients who expressed their wish to die at home, an estimated 55% actually died in a hospital. Evidence indicates that a reason why patients are not receiving the care they want is a problem with communicating their end-of-life care goal. Nation-wide studies report that as few as 30% of patients have actually had discussions with their physician or family about their end-of-life care preferences (The Conversation Project, 2013). The gap in these statistics suggests that while many patients know they do not want invasive or intensive care, they do not express those wishes to the people who can legally carry them out.

When patient wishes are not known, the consequences can be emotionally, spiritually, and economically painful for all involved (Dumont et al., 2006; Khandelwal et al., 2015; Prendergast, 2001). Family caregivers and surrogate decision makers must make the most important of end-of-life medical decisions without clear guidance, causing conflict, pain, and extended periods of grief (Badr, Smith, Goldstein, Gomez, & Redd, 2015; Dumont et al., 2006). Families may also be saddled with the expenses of costly, but futile care the patient never wanted (Dixon, Matosevic, & Knapp, 2015; Marckmann, 2013). Moreover, healthcare professionals must help facilitate these decisions for families, bearing this stress, emotional work, and the ethical dilemmas these situations create (Larson & Yao, 2005). Because of these critical outcomes, research in health policy, medicine, and communication is needed to focus on

increasing the quality of advance care planning communication so that patient goals and preferences for care are known and recorded, and surrogate decision-makers can make decisions that are concordant with these wishes.

In the past 10 years, advance care planning has been redefined as an iterative communication process (Sudore & Fried, 2010). No longer a one-step process of filling out legal documents about withdrawing care, advance care planning has been understood as a process of expressing patient goals, preferences, and wishes for end-of-life care to physicians, family members, and surrogate decision makers (Sudore et al., 2008). Redefining advance care planning in this way brings immediate attention to why it is so difficult. It involves many individuals; it takes place over the course of many interactions that involve the sensitive and complicated matter of making decisions for another person; and it involves in some cases complex healthcare concerns that change as a patient's health condition worsens (Lum et al., 2016; Sudore & Fried, 2010). If the ideal outcome of such planning is medical care concordant with patient wishes and goals, then surrogate decision-makers and family members must not only understand the patient's wishes but be willing and able to communicate with a medical team when the patient cannot.

The challenge of thinking about end-of-life care enshrouds this process. To engage in advance care planning for end-of-life care means a person must contemplate the circumstances of their death and consider how decisions might be made for them. For people who are very ill and closer to death, this thought exercise is urgent, but for those who are not dying, this exercise is extraordinarily difficult (Temel et al., 2010). In early advance care planning, a process that has been shown to have positive effects on end-of-life care, individuals face a form of "radical uncertainty": a set of possibilities so that are so numerous and remote that they tend to

overwhelm the ordinary decision-making processes (Tuckett & Nikolic, 2017). Because of these challenges, this area of study is ripe for the application of communication theories.

Finally, communication in advance care planning is challenging because the familial and clinical interactions that make up the process take place within a complex ecological system. Situating advance care planning in a broader ecological system offers a perspective that considers not only what unfolds in the interactions taking place, but also the influences of the social context in which the interactions are situated (Street, 2003a). Any interpersonal interaction, whether it is with a family member or with a physician, is driven by both the personal factors the interactants possess, as well as the environmental factors in which the interaction takes place (Ritchie & Fitzpatrick, 1990). In other words, these interactions -- an individual's communicative actions in relationship to others -- are first of all influenced by the individual's personality traits, attitudes, goals, and beliefs (Bronfenbrenner, 2001; Moran et al., 2016) as well as how they coordinate their responses given the communication of their interlocutors (Street, 2003a). Second, these interactions are also influenced by an environment that includes the cultural values and belief. Third, they are influenced by the political and legal forces at work outside of the interaction, as well as by the organization and environment in which the interaction takes place. Finally, even media and technology used shapes the interactions (Street, 2003a). Changes to any of these factors can affect the way the interaction plays out, the perceived success of the interaction, and each participant's satisfaction with the relationship between the interactants (Kazak, 1989; Moran et al., 2016).

Advance care planning primarily consists of two very different types of interactions: the clinical encounter between patient and their physician, and encounters between the patient and their family. For the purpose of this writing, family includes those with whom the patient shares

a deep sense of intimacy, as well as a shared history and a shared future (Koerner & Fitzpatrick, 2002a). This project focuses on both types of interactions. The clinical encounter with the physician can be influenced by patient and physician personal factors, such as their personalities and goals for the encounter, as well as the environmental forces at work in the clinic, such as the culture of the healthcare organization, workflow, quality improvement initiatives, and the legal obligations of the physician (Street, 2003a). In a family setting, advance care planning conversations are shaped by the personal characteristics of the family members, as well as larger family communication dynamics, such as the family's ability to have open conversations about death, the family's ability to make collective decisions, and the home environment (Rogers, 2001). Because advance care planning takes place in the clinical and in the familial environments, both types of interactions inform the patient's preferences for care and ultimately the care they receive. The ecological factors of both interactions thus fit together to create a larger ecology, which impacts the patient's ability to openly discuss his or her preferences for end-of-life care and the patient's ability to make decisions about end-of-life care. Moreover, when considering these interactions in total, an argument can be made that theories and concepts traditionally used in each separate environment inform one another and can actually be used to complement one another.

Using an ecological perspective, this project focuses on personal and communicative factors affecting advance care planning situated within three different contexts: an individual cognitive context, the familial context, and the clinical context. The aim of this project is to understand the way key variables in advance care planning interactions work within these different contexts. This project consists of three studies, each of which employs different methods. See Figure 1 for an overview of the entire project that details key features of each

study. Study One focuses on individual beliefs and attitudes toward family and physician openness about death and surrogate decision-making using a survey. Study Two uses a qualitative approach to focus on openness and decision-making in advance care planning interactions in a family setting. Finally, Study Three uses a mixed-methods approach to analyze secondary data from patient-clinician interactions in a clinical setting, focusing on discursive strategies physicians and patients use during conversation about end-of-life care and decision-making strategies.

Dissertation Overview
Three Studies of the Communication Ecology of Advance Care Planning

Overarching Research Questions:

- **How do patients talk about advance care planning with physicians and family surrogate decision makers?**
- **How do ecological factors affect individual participation these conversations?**
- **How are conversations in these different environments similar/dissimilar?**

	Study One	Study Two	Study Three
Title	The Impact of Openness on Family Communication Patterns on Concordance and Surrogate Decision-Making Preferences	Real Talk about Death and an Extended Typology of Family Communication Patterns in Advance Care Planning Decision-Making	Patient Engagement and Physician Responsiveness in Advance Care Planning Consultations: A Mixed-Methods Study
Focus	Influence of patients' and surrogates' beliefs and perceptions about communication on concordance and decision-making preferences in advance care planning.	How patients and family surrogate decision-makers talk about advance care planning, and how their ideas about advance care planning reflect deeply held family communication patterns.	How patients and physicians talk about advance care planning, and how that talk is reflected measures of patient engagement and physician responsiveness.
Method	Quantitative	Qualitative	Mixed
Environment	Inner Environment of Individual	Family Microsystem	Clinical Microsystem
Research Aims and Questions	Aim 1: Describe the degree of concordance between patients' and surrogates' assessments end-of-life care preferences, attitudes toward advance care planning, end-of-life care priorities, and surrogate decision-making preferences. Aim 2: Describe the effect that each dyad members' perceptions of the other's openness about death and dying has on measures of patient-surrogate concordance. Aim 3: Examine the relationship between Family Communication Patterns Theory and concordance.	RQ1: How do patients and their family surrogate decision makers talk about death when they are asked to discuss hypothetical scenarios involving end-of-life care decisions? RQ2: How can family communication microsystems be characterized in an effort to describe members' collective management of uncertainty and potential for decision-making conflict in advance care planning?	RQ1: How are issues related to advance care planning and end-of-life care decision making expressed by patients and addressed by physicians in clinical interactions? RQ2: How do the ways patient and clinicians talk about advance care planning affect the patient engagement and physician responsiveness ratings assigned to the conversations by naïve observers?

Figure 1. An Overview of Studies Included in this Dissertation.

CHAPTER II

LITERATURE REVIEW AND PROJECT RATIONALE

This literature review covers the theories and concepts from three major areas that undergird this study: the ecological perspective, medical decision-making, and family decision-making. It provides a foundation for studying these three ideas together and a basis for the three studies undertaken in this project. It finally provides a rationale for taking a mixed-methods approach to research in this area.

The Ecological Perspective

At its most basic, an ecological perspective examines the interrelatedness of an organism and its environment (Emery & Trist, 2012). Seeing the interconnected relationships among natural systems is so fundamental to scientific observation that much of the past 400 years of scientific research is rooted in this perspective. For at least 30 years, communication scholars have incorporated the concept of an ecology of communicative acts in a number of ways, including cybernetics, the social-ecological approach to health communication, network theory, and systems theory (Craig, 1999). The common tenet in these theories is that within any environment, complex systems are at work, interacting and affecting one another, so even though parts of the system can be examined on their own, the complete system should also be studied as a whole.

Because of the ubiquity of the ecological perspective, then, there are many communication theory traditions from which to draw for this project. The early work of Urie Bronfenbrenner (1977) provides a solid ecological framework for understanding the way

multiple contexts affect an interaction (Moran et al., 2016). Thus this project will draw from Bronfenbrenner's work to characterize the ecological systems at play in advance care planning, as well as Street's (2003a) ecological perspective on medical encounters to discuss specific attributes of these systems that affect communication.

Bronfenbrenner's (1977) early work on ecological systems theory is grounded in the study of the developing human in the context of their environment. Central to this theory is the importance of context; development is influenced by the multiple, intersecting environments that create a context in which each individual grows. In addition to physical environments, this model includes in it individual relationships, culture, institutions, and legal and political systems (Bronfenbrenner, 1977). These social structures are nested in layers and include at their core the individual's microsystem and the individual's immediate setting. In the context of advance care planning, the microsystem includes the places where the conversations and actions of advanced care planning take place, such as at home with family, in the clinic with the physician, and at the hospital (Street, 2003a).

The next layer, the mesosystem, includes the interaction among the individual's microsystems, creating an interdependent of microsystems (McIntosh, Lyon, Carlson, Everette, & Loera, 2008). Mesosystems occur when a link is made between two microsystems by an individual. For advance care planning, mesosystems are particularly important. In the process of advance care planning, individuals link all of their microsystems, including family, physicians, and care facilities, among many others when making end-of-life care decisions. Two of the most important microsystems that intersect for patients engaged in advance care planning are their interactions with family and with their physician. Both of these microsystems impact one another to form the mesosystem in which the patient makes advance care planning decisions. The way a

patient and physician can openly discuss and make decisions about palliative care options in a clinic visit, for example, will influence the way the patient discusses and makes decisions about these options with family members. Both microsystems involve different environmental factors, and different conversations will take place in each microsystem, but the type of care the patient ultimately receives and whether that care is concordant with patient goals depends on the intersection of these microsystems.

While research has sought to articulate which microsystems are involved in the advance care planning process, none have sought to understand them in tandem using this type of ecological approach. Although they will not be studied in this work, Bronfenbrenner articulated three more layers of systems: the exosystem, which includes larger systems such as neighborhoods, social networks, and government agencies; the macrosystem, which includes larger legal, social, and cultural institutions; and the chronosystem, which deals with changes in these systems over time (Bronfenbrenner, 1977).

Over time, Bronfenbrenner made many changes to his initial model. One of the most important changes is relevant to this study: the focus on personal factors that influence the individual's development (Bronfenbrenner, 2001). These factors include personal characteristics such as gender, race, and education, as well as characteristics Bronfenbrenner termed resource and force characteristics. Resource characteristics include skills, abilities, attitudes, and beliefs. Force characteristics include motivation, desire, and persistence (Bronfenbrenner, 2001). These factors are particularly important to consider in advance care planning, as end-of-life care preferences are highly idiosyncratic, depending on attitudes, personal characteristics, and desires (Singer, Martin, & Kelner, 1999). Advance care planning conversations with physicians and family members are dependent on personal, resource, and force characteristics. Individual

characteristics of all of these interactants, such as religious beliefs about death, attitudes toward pain and suffering, and the desire to engage in conversations all affect each individual's participation in open conversations about the end of life, as well as their participation in making these decisions (Kramer, Kavanaugh, Trentham-Dietz, Walsh, & Yonker, 2009; Rodenbach, Rodenbach, Tejani, & Epstein, 2016; Street, 1991)

Although Bronfenbrenner's models are useful in this study for identifying the way micro- and mesosystems impinge upon advanced care planning decisions, his model is intended to be used to model human development and not interpersonal communication specifically. Theories and concepts specific to interpersonal communication help to better identify the elements of interaction at work in each of the microsystems. That is, using the ecological approach to examine communication environments brings the larger ecology to life with a focus on communication behaviors. This model has been used in research both implicitly and explicitly in the clinical and family microsystems.

In their ecological model of the clinical encounter, Street et al. (2003) outline specific factors that influence clinical encounters. Centering on the interpersonal context of the clinical encounter, again, a microsystem in Bronfenbrenner's (1977) larger model, Street et al. (2003) detail the pre-dispositional, cognitive-affective, and partner influences that impact the patient-physician interaction. Pre-dispositional factors that influence these encounters include specific sets of Bronfenbrenner's individual characteristics. For physicians, these characteristics include their view of the patient's role in the interaction, their clinical specialty, and their capacity for empathy. For patients, these characteristics include their level of education, age, and capacity for self-expression (Street, 2003a).

But because Street et al. (2003) are also concerned with examining behaviors during the interaction, they also consider the cognitive-affective factors (e.g., goals, motivations, perceptions) that affect how patient and physician will respond to one another. Finally, Street et al. (2013) note that patient and clinician have mutual influence on one another, as the communicative actions of one provides both constraints and opportunities for subsequent responses from the other. This in part explains research indicating that doctors give more information to patients who ask questions (Clayton et al., 2007; Street, Gordon, Ward, Krupat, & Kravitz, 2005) and patients often are more involved in the interaction when the physicians solicits their views and preferences (Street et al., 2005).

Although there is not a single, specific ecological model for family communication, personal characteristics and family communication patterns will influence family conversations. In addition to individual traits such as age, gender, and education, families tend to create and adhere to communication rules (Rogers, 2001). Families create a shared social reality by establishing communication practices (Koerner, Fitzpatrick, Braithwaite, & Baxter, 2006). According to Family Communication Patterns Theory, these practices often dictate how openly family members will discuss topics with one another and outsiders, as well as expectations for dealing with conflicting views (Koerner & Fitzpatrick, 2002b; Koerner et al., 2006). As such, interactions within the family microsystem are shaped by the communication environment the family has created.

A family's communication environment thus influences members' ability to engage in conversations about sensitive and private matters such as healthcare decisions (Pecchioni & Nussbaum, 2000; Wittenberg-Lyles, Goldsmith, Demiris, Oliver, & Stone, 2012). Because advance care planning involves discussion of death, the openness with which families will

discuss these decisions depends on the family's communication environment (Scott & Caughlin, 2015). The depth of the discussion, the negotiation of conflicts, and the level of participation by family members in these conversations are all influenced by the long-held rules the family uses to communicate (Scott & Caughlin, 2015; Shin et al., 2016; Wittenberg-Lyles et al., 2012).

Figure 2 presents an integrated ecological model of communication in advance care planning that is based on the work of Bronfenbrenner and Street.

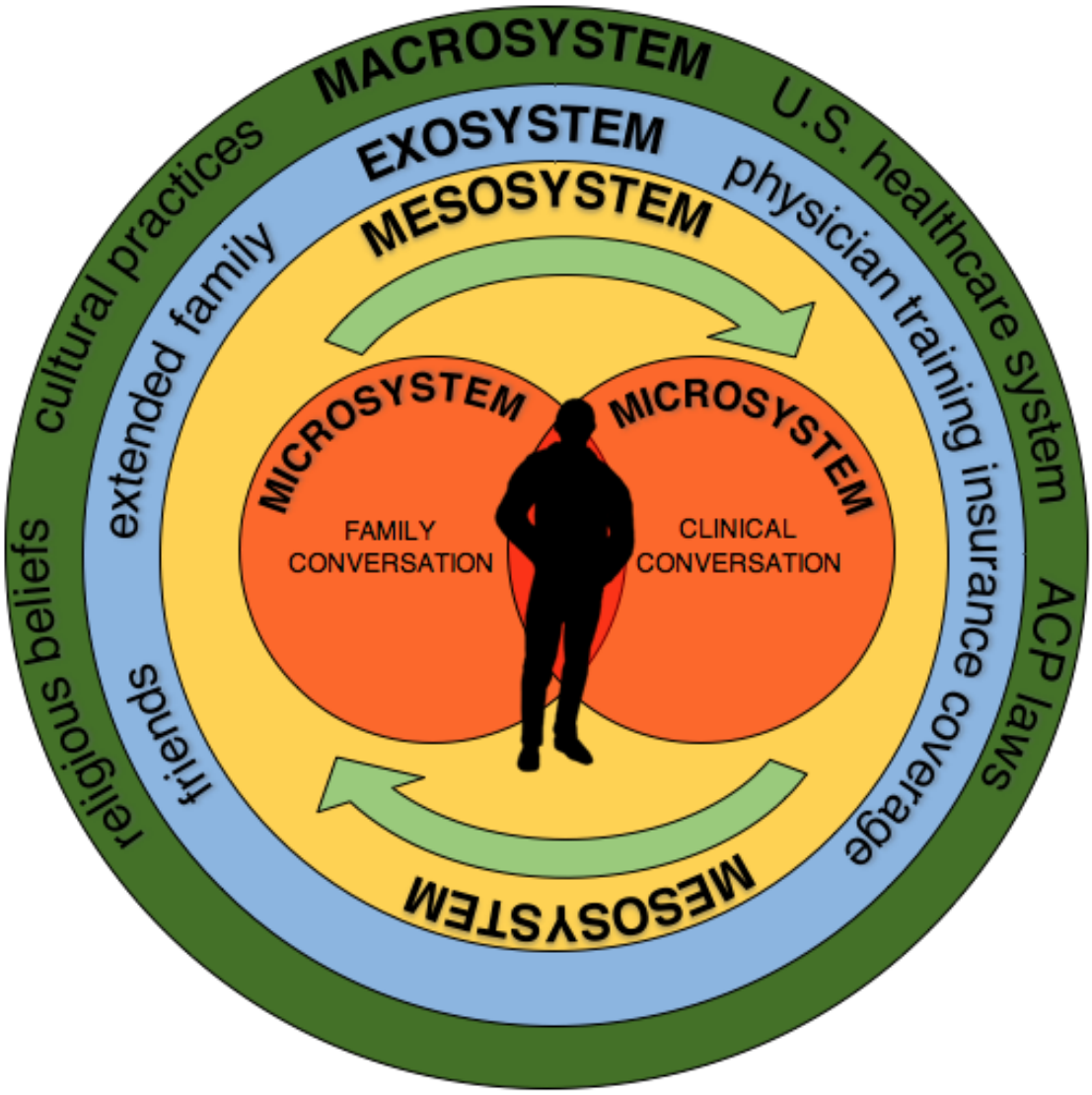

Figure 2. Integrated Ecological Model of Communication in Advance Care Planning.

Decision-Making in the Clinical Microsystem

Advance care planning presents unique decision-making challenges in interpersonal interactions. Critics of advance directives have noted that legal language in these documents often asks about whether the patient wishes to receive treatment and for the appointment of a surrogate decision maker. As Sudore and Fried (2010) point out, advance care planning is much less about envisioning specific circumstances than it is about expressing patient goals and values, as well as appointing a surrogate decision-maker and deciding how much latitude that decision maker should have. The reason for focusing on expressing goals and values as well as appointing a surrogate, Sudore and Fried argue, is that the trajectory of illnesses and the types of decisions that must be made are difficult to anticipate. A patient with terminal cancer, for example, may have many different palliative options, each of which carry different risks and benefits. The choice under these circumstances, weighing risks and benefits, can be unclear and much more a matter of choosing the option that most lines up with the patient's values (Hoerger et al., 2013).

Challenges to ensuring care concordant with patient values and goals include individual attitudes and beliefs. Biases, forecasting errors, and emotions such as surrogate guilt influence surrogates' abilities to use advance directives honoring patients' wishes (Halpern, 2012). In a study of spouses' predictions of one another's end-of-life care wishes, at least 30% were either wrong or uncertain as to their spouse's wishes (Moorman & Carr, 2008; Moorman, Hauser, & Carr, 2009). While a number of factors likely affect a physician and a surrogate's ability to make decisions, one factor that plays into this problem is projection bias (Loewenstein, 2005). Projection bias occurs when an individual projects their own current affective state onto the future. The problem with projection bias in advance care planning is that physicians and

surrogates tend to project their own current attitudes toward death onto others (Lowenstein, 2005).

Clinical decision-making presents unique challenges because of the differing ways patients and physicians perceive their roles in this situation. The standard that most healthcare institutions currently strive to achieve is shared decision making (Epstein & Street, 2011; Frosch, May, Rendle, Tietbohl, & Elwyn, 2012). This term has changed meaning over time, but in general, it indicates an effort on the part of physicians and patients to collaboratively share their thoughts, feelings, and preferences while deciding on patient options (Hajizadeh, Uhler, Herman, & Lester, 2016; Müller, Hahlweg, & Scholl, 2016). Although measures of shared decision making in clinical conversations differ widely, several common elements include a discussion of all applicable options, the pros and cons of each option, patient preferences for care, patient preferences for who makes the decision, and checking for patient understanding (Clayman, Makoul, Harper, Koby, & Williams, 2012). These discussions will look different in different clinical contexts (Kon, 2010). In an advance care planning consultation, patients and physicians will ideally discuss patient goals for care, end-of-life care options, patients' reasons behind their choices, and their preferences for a surrogate decision maker (Clayman et al., 2012; Hajizadeh et al., 2016; Müller et al., 2016). However, there are many obstacles to shared decision making in advance care planning, including adequate time for discussion, aversion to the topic of death, and the need to maintain hope (Epstein & Street, 2011; Hagerty et al., 2005).

When patients and physicians have advance care planning conversations, the willingness of both physicians and patients to engage in shared decision-making will affect the quality of communication about advance care planning, end-of-life care, and death (Mebane, Oman, Kroonen, & Goldstein, 1999; Silveira, DiPiero, Gerrity, & Feudtner, 2000; Singer et al., 1999).

In addition to the individual factors related to one's comfort and openness to discussing these issues, the way patients and physicians respond to one another and influence one another are important factors in the extent to which shared decision-making will be accomplished (Pearlman, Cole, Patrick, Starks, & Cain, 1995). Some studies indicate that physicians wait for patients to broach the subject because physicians want to maintain patient hope and to avoid an uncomfortable subject (Hagerty et al., 2005). Patients will also wait for physicians to initiate the conversation because they feel that the physician is in charge of such matters (Parker et al., 2007). Even when the subject matter is opened up, patients and physicians tend to work toward an outcome—a decision about a course of palliative care, for example, or completion of an advance directive—without eliciting patient motives for the decision or their goals for care, their emotional state, or their spiritual convictions (Badr et al., 2015). By not considering these factors, physicians and patients are not able to help prepare surrogates to make end-of-life care decisions.

A final consideration of medical decision-making relevant to the studies here is the concept of autonomy. Patient autonomy has traditionally been defined as an individual's ability to make their own choices and to assert their desires (Clayman, Roter, Wissow, & Bandeen-Roche, 2005; Pecchioni & Nussbaum, 2000). But autonomy is a much more complicated concept (Epstein, 2013) because, as the ecological model suggests, individuals' environments are full of other people. Many have written about challenges to traditional definitions of autonomy, using legal, ethical, and social-science lenses (Channick, 1999). In using an ecological lens to study communication behaviors, this study seeks to examine the influences patients and physicians have in their communication environment that inevitably affect the patient's and their surrogate decision-maker's choices.

Decision-Making in the Family Microsystem

Decision-making among family members in end-of-life care also presents challenges. Although the importance of communication among family members making these decisions has been emphasized, families often face conflicts that are fraught with heightened emotions (Dumont et al., 2006). Families also vary in the degree to which they will share responsibility for making these decision; some families are comfortable sharing responsibility, while others prefer to defer power to a single individual (Wallace, 2015). Individual members often have differing levels of health literacy, caregiving abilities, and information sharing with the patient. These attributes sometimes conflict with the family role the individual is expected to play in surrogate decision making.

A concept that is useful for gauging the potential for family discussions about sensitive issues is openness. Openness has been operationalized in a number of ways (Goldsmith & Domann-Scholz, 2013; Mesters et al., 1997) On an individual level, openness has been defined as an individual's willingness to discuss a particular topic ("I'm open to discussing death"), as well as to generally characterize communication in a relationship ("we're open with each other") (Goldsmith & Domann-Scholz, 2013; Mesters et al., 1997). In families, there is a continuum of collective openness; while some families are more willing to talk about sensitive subjects, others create environments in which some subjects are taboo (Ritchie & Fitzpatrick, 1990).

In interactions involving patients and physicians as well as interactions involving families, openness has been used to characterized the rapport between two individuals, as well as a sense of community among family members (Arora, 2003; Goldsmith & Domann-Scholz, 2013). In these contexts, openness has been measured using self-report scales that ask individuals to characterize the level of openness they perceive, as well as behavioral measures,

such as the number of instances in which interactants discuss a particular topic (Goldsmith & Domann-Scholz, 2013; Koerner & Fitzpatrick, 2002b; Ritchie & Fitzpatrick, 1990).

In describing the different meanings of open communication, Goldsmith and Domann-Scholz (2013) explain that in complex health situations, measures of openness should also attend to precisely which aspects of a situation individuals are open about. When discussing complex issues such as advance care planning, it is important to tease apart whether individuals are open about the facts of the situation, their feelings about it, and their motives for making decisions. Goldman and Domann-Scholz (2013) note that individuals might characterize themselves as open generally toward health matters such as advance care planning, but might only be open, for example, to discussing facts about their advance directive, but not their feelings about death. Thus it is important to specify the target of the measured openness.

A family's communicative environment characterized family members' openness and ability to engage in conversations and decision-making about advance care planning (Wittenberg-Lyles et al., 2012). An unwillingness to talk about death among family members corresponds with less willingness to explore advance care planning options (Brown et al., 2014). Even interventions intended to educate individuals about end-of-life care do not increase family members' willingness to engage with the subject (Claxton-Oldfield, Crain, & Claxton-Oldfield, 2007). This has led others to propose that patterns of openness and willingness to talk about advance care planning are deeply embedded in families—across generations of family, there are relationships among members' death anxiety, openness about death, and willingness to engage in advance care planning (Freytag & Rauscher, 2017).

A related, but different way of thinking about family decision-making whole-cloth is to characterize the environment in which the family both communicates and makes decisions.

Communication theories such as Family Communication Patterns Theory (FCPT) have established that members of a family encourage one another to adopt long-standing behaviors and beliefs about communication (Koerner & Fitzpatrick, 2002). In fact, most of an individual's formative communicative experiences about health occur within their family communication environment (Rogers, 2001). Moreover, Family Communication Patterns have been linked to psychosocial outcomes (feelings of closeness, self-concept, mental health), behaviors (speech acts, conflict behaviors), and information processing (processing media messages) (Schrodt, Witt, & Messersmith, 2008).

This theory is rooted in the psychological concept of co-orientation (Koerner & Schrodt, 2014). Co-orientation occurs when multiple individuals square their perceptions of reality with what they believe others around them perceive, and it occurs among family members when they seek to coordinate those perceptions and to create a shared reality (McLeod & Chafee, 1972). According to McLeod and Chafee (1972), families use both a socially oriented process of building relationships among members and a concept-oriented process of communicating ideas to construct a shared reality. That is, family members negotiate their understanding of the world based on their both their individual perceptions as well as a shared understanding with their family members. McLeod and Chafee (1973) argue that families negotiate these shared understandings in different ways, with some families creating a stronger, more rigid sense of shared ideas, and others more open to challenging one another's perceptions.

Thus, in FCPT, family communication patterns are described in terms of two processes: a conversational orientation, in which family members discuss the nature of an issue communally; and a conformity orientation, in which family authority dictates the nature of an issue for the family (Ritchie & Fitzpatrick, 1990). Families that are high in conversation orientation tend to

discuss issues and ideas freely; the range of topics is broad, with even sensitive and controversial subjects discussed openly. Families that rank low in conversation orientation tend to avoid conversation and are less likely to discuss emotions and sensitive topics (Fitzpatrick, 2004). Families that rate high in conformity orientation emphasize obedience to family authority and avoid conflict; they seek harmony among the ideas among members. Families low in conformity orientation see members as equals, valuing the individual perceptions of each member, even when they conflict (Koerner & Fitzpatrick, 2006).

These characteristics of family communication environments are relevant here not only because they seek to describe how willing a family might be to discuss a complicated and difficult topic such as death, but because they also describe a style of communication that can be coordinated with different styles of decision-making (Koerner et al., 2006). While families that skew toward conformity might depend on a family authority for decision-making guidance, one skewed less in that direction might have members who are encouraged to rely on their inner sense of judgment. Moreover, families hew to deeply held patterns of communication during times of health crisis (Northouse et al., 2007). Thus these patterns can describe something more than communication habits in this context: the fundamental ways people both make decisions and expect decisions to be made. This point is particularly relevant for advance care planning, as it involves much more than individuals making decisions for themselves; it involves the way individuals expect decisions to be made for them by their family members.

A Mixed Methods Approach

It is finally important to consider why this project includes studies that employ both qualitative and quantitative methods. Combining methods is a challenge, not only because of the sometimes competing and seemingly incongruent epistemologies that guide them, but because it

is difficult to reconcile these different types of evidence against one another (Creswell, 2013). But this combination is important for this project for two key reasons. First, it is important because this project takes a problem-based approach to the study of the communication ecology of advance care planning. As discussed in the Chapter One, individuals often do not engage in advance care planning in the way that they should, and inquiry into why and how they should is a relatively new inquiry for communication scholars. Thus, evidence in all forms that illuminates the breadth and depth of communication issues in this area and lays a foundation for developing effective interventions and developing context-specific theories should be collected.

Second, the use of mixed methods in this study is important because advance care planning is still being redefined as a social process (Sudore & Fried, 2010). This means that there is a great deal of variation in "what" precisely advance care planning involves. What do individuals think it means? What do they actually talk about? How do they talk about it? These are all questions that undergird this inquiry. Again, to examine these questions involves not just a sense of the breadth of the communication issues that occur in this area, but the depth of the content of these conversations.

CHAPTER III

STUDY ONE

THE IMPACT OF OPENNESS AND FAMILY COMMUNICATION PATTERNS ON PATIENT-SURROGATE CONCORDANCE IN ADVANCE CARE PLANNING

Study Aims and Rationale

At the center of the ecology of advance care planning conversations is the individual. Each individual's perceptions, attributes, and attitudes color their participation in these conversations (Street, 2003a). Individual characteristics affect their participation in conversations, their assessment of the quality of the conversation, and their perception of their conversational partner (Street, 1991). The overarching goal of Study One, then, is to assess individual attitudes, attributes, and perceptions that might affect communication between patient and surrogate decision maker. Study One thus considers patients' and their surrogates' attitudes toward making end-of-life care decisions, their perceptions of openness about death, and their assessment of one another's attitudes and preferences. In addition to these attitudes, it also assesses the attitudes and perceptions patients and their surrogates have about communication within their family as well as the level to which they can be open with one another about death and dying, which undergird their participation in advance care planning. This study thus aims to ultimately describe how these attitudes, attributes, and perceptions influence concordance, or agreement, between patient and surrogate decision-makers about the patient's end-of-life care preferences and how the family communication environments in which patients and surrogates operate influence their ideas about how surrogates should make decisions. In the study rationale

that follows, each of three study aims of this work is first identified, and then specific hypotheses and questions related to each aim are stated.

Aim 1: Describe the degree of concordance between patients' and surrogates' assessments end-of-life care goals, attitudes toward advance care planning, end-of-life care priorities, and surrogate decision-making preferences.

Concordance between patients and their surrogate decision makers has been studied widely in advance care planning decision-making (Desharnais, Carter, Hennessy, Kurent, & Carter, 2007; Engelberg, Patrick, & Curtis, 2005; Layde et al., 1995). A systematic review of concordance studies in advance care planning has found that surrogates accuracy when predicting patient preferences is around 68% (Shalowitz, Garrett-Mayer, & Wendler, 2006), but explanation as to why there is inaccuracy remains varied. Biases, forecasting errors, and emotions such as surrogate guilt all likely influence surrogates' ability to use advance directives to honor patients' wishes (Halpern, 2012). Even spouses, who share among the most intimate of relationships, have predicted one another's end-of-life care wishes either incorrectly or expressed uncertainty about those wishes at least 30% of the time (Moorman & Carr, 2008; Moorman et al., 2009).

There is a significant difference between the majority of the measures use to assess concordance in previous studies and the ones use here. Most previous measures have assessed patient and surrogate responses to a specific set of medical circumstances, either a hypothetical situation or a current medical condition (Bravo, Sene, & Arcand, 2017; Shalowitz et al., 2006; Waller et al., 2018). For example, previous studies have asked surrogates and patients to respond to whether the patient would want CPR if the patient had a particular incurable condition, or they

have asked patients with terminal illness whether they would prefer to receive care at home (Shalowitz et al., 2006).

One of the differences between the previous studies and the current study is that in the current study none of these measures used for concordance correspond to a specific medical condition. The reason for this is that current research in advance care planning has demonstrated that early advance care planning, which takes place long before a patient is terminally ill, is more effective when it involves more global, holistic discussion of patients' goals for care and decision-making preferences (Sudore & Fried, 2010; Sudore et al., 2008). Additionally, the measures used in this study cover a wider array of advance care planning domains. That is, they ask not only about patient care preferences (e.g., a preference for end-of-life care at home), which has been done in many studies, but they also ask about patients' motives for engaging in advance care planning, their preferences for surrogate decision making, and patient priorities for their care. While these other measures have been assessed piecemeal in previous studies, none has included measures across all of these domains (Marks & Arkes, 2008; Shalowitz et al., 2006). With these key differences in mind, this study asks the following questions:

RQ1: What is the level of concordance between patient and surrogate global assessments of patient end-of-life care goals?

RQ2: What is the level of concordance between patient and surrogate global assessments of patient attitudes toward advance care planning?

RQ3: What is the level of concordance between patient and surrogate global assessments of patient end-of-life care priorities?

RQ4: What is the level of concordance between patient and surrogate global assessments of patient surrogate decision-making preferences?

Aim 2: Describe the effect that each dyad members' perceptions of the other's openness about death and dying has on measures of patient-surrogate concordance.

Studies measuring openness among family members suggest that a willingness to talk about death is a key element of achieving concordance, though this claim has not been explicitly tested. While some families have more willingness to engage in conversations about sensitive subjects, others create environments in which some subjects are taboo (Koerner & Fitzpatrick, 2002b; Koerner et al., 2006). But openness within a family is contextual, depending on the subject matter discussed (Badr, 2016; Goldsmith & Miller, 2015). Goldsmith and Domann-Scholz (2013) suggest that openness with regard to healthcare issues includes the frequency of conversations about the subject, how the conversations are initiated, the discussion of emotions, the discussion of tangible facts, and the discussion of underlying ideas. These dimensions of openness are of particular interest in relationship to death, the incredibly sensitive and emotional issue that is at the root of advance care planning for end-of-life care.

RQ5: Do patient and surrogate assessments of one another's openness about death and dying predict concordance between patient and surrogate global assessments of patient end-of-life care goals?

RQ6: Do patient and surrogate assessments of one another's openness about death and dying predict concordance between patient and surrogate global assessments of patient attitudes toward advance care planning?

RQ7: Do patient and surrogate assessments of one another's openness about death and dying predict concordance between patient and surrogate global assessments of patient surrogate decision-making preferences?

RQ8: Do patient and surrogate assessments of one another's openness about death and dying predict concordance between patient and surrogate global assessments of patient end-of-life care priorities?

Aim 3: Examine the relationship between Family Communication Patterns Theory and concordance.

Finally, this study seeks to examine the relationship between family communication patterns and patient and surrogate concordance. As discussed in the introduction of this project, Family Communication Patterns Theory (FCPT) holds that families maintain long-established patterns of conversation and conformity orientation (Koerner et al., 2006). The assessment of a family's conversation and conformity orientation imply preferences for communication and decision-making because these orientations dictate the level to which families will engage in conversation and the level to which members are to seek harmony and agreement in their decision-making. Family communication patterns have been linked with differences in communication and decision-making skills and can often predict behaviors and attitudes (Schrodt, Witt, & Messersmith, 2008). Conversation orientation has been found to be related to outcomes such as shared understanding, confirmation, and acceptance (Koerner & Schrodt, 2014; Schrodt et al., 2008). Conformity orientation has been shown to have a negative relationship to conversation orientation with regard to these outcomes (Keating, 2016).

These two dimensions have been used to create a typology of family communication environments. The four types of family communication environments include protective, consensual, laissez-faire, and pluralistic (Koerner et al., 2006). Each type has been found to have a relationship to the ways families make decisions, process information, and form relationships with others (Schrodt et al., 2008). Pluralistic families have high conversation orientation and low

conformity orientation. These are family members who engage in deliberative conversation. They are families in which members value conversation, and they also value their individual autonomy (Koerner et al., 2006). Protective family communication environments are low in conversation orientation and high in conformity orientation and fall into the protective category of family communication environments (Koerner & Fitzpatrick, 2002a, 2002b). Obedience is emphasized in these families and valued more than open communication (Koerner & Fitzpatrick, 2002a, 2002b). Families high in conversation orientation and high in conformity orientation create a consensual family communication environment. These families have a strong sense of family structure and common ideas and find it important to align themselves with a family leader. Within these families, there is a "pressure to agree and preserve the existing hierarchy" (Koerner et al., 2006, p. 15). Finally, laissez-faire families are low conversation orientation and low conformity orientation environments (Koerner & Fitzpatrick, 2002b). Laissez-faire family members have limited interactions with family and do not value communication with one another (Koerner et al., 2006).

This study seeks to show that family communication patterns influence concordance between patients and surrogates by positing the following hypotheses:

H1: Patient and surrogate family communication environment type will influence patient and surrogate concordance on patient end-of-life care preferences.

H2: Patient and surrogate family communication environment type will influence surrogate concordance on patient attitudes toward advance care planning.

H3: Patient and surrogate family communication environment type influence patient and surrogate concordance on patient surrogate decision-making preferences.

H4: Patient and surrogate family communication environment type will influence patient and surrogate concordance on patient end-of-life care priorities.

Methods

Design

This study involves data collected through an online survey created in Qualtrics. Upon IRB approval, survey links were sent to potential participants who are associated with the online groups described below. Participants who are over 55 were asked to take the survey found in Appendix A. Early on in the survey, patients were asked to identify and provide an email address for a primary surrogate healthcare decision-maker who is also a family member. Once the participant (hereinafter "patient") completed the survey, the primary surrogate received a link to the surrogate survey found in Appendix B. Patient and surrogate data was matched through the email addresses collected. Participants were offered a $10 Amazon gift card for completing the survey.

Participants

This study focused individuals over 55 ("patients") and their surrogate decision makers. This population was chosen because patients over 55 are in an ideal position to engage in early advance care planning, and they are more likely to have considered end-of-life care (Kass-Bartelmes & Hughes, 2004). At the beginning of the survey, each individual over 55 was asked to provide a first name and email address of a family member who they thought would likely be their surrogate healthcare decision maker for their end-of-life care. The surrogate healthcare decision maker was then sent a link to the surrogate version of the survey.

In the recruitment materials, the key terms "family member" and "surrogate healthcare decision maker" were defined using current literature in the field. In an effort to be as inclusive

as possible of different family structures, the materials defined a family member as "someone with whom you share intimate, strong ties and a sense of commitment; this person does not necessarily have to be related to you by blood or marriage." This definition was written to comport with the transactional model of family, which holds that given the fluidity of family structures, family can be defined as a group of intimates that share a set of experiences (Koerner & Fitzpatrick, 2002a; Noller & Fitzpatrick, 1993). Surrogate health care decision maker was defined as "the person who will make decisions for your care when you can no longer do so," which is a simplified version of the legal definition (Fritch, Petronio, Helft, & Torke, 2013).

Recruitment

Participants were recruited through online message boards, Facebook groups, and email lists targeting those over 55. Recruitment messages were sent to group administrators, online message board moderators, and email list monitors. These individuals were asked to distribute the recruitment message to their members. The recruitment message described the study and contained a link to the study. Participants clicked on the link to participate in the survey.

The online message boards, discussion groups, and email lists include retirement organizations, such Medicare discussion boards and social groups that specifically target the interests of those over 55. This recruitment method was chosen to help ensure that participants had enough technology skills to complete the survey and to recruit a surrogate decision-maker to take the survey (de Bernardo & Curtis, 2013). The following web links represent some of the message boards and/or email lists used for recruitment (only national links are provided here; local websites also exist for some):

- https://americanseniors.org/
- https://www.redhatsociety.com/

- https://amac.us/
- https://www.ncoa.org/
- https://retiredamericans.org/
- http://www.seniorforums.com/
- http://www.seniorsonly.club/

Upon completion of the survey, all participants, patients and surrogates, were offered a $10 digital Amazon gift card.

Measures

The surveys for patients and surrogates included measures of health status, relational closeness, openness, end-of-life care goals, attitudes toward advance care planning, end-of-life care communication priorities, surrogate decision-making preferences, communication self-efficacy, and family communication patterns (See survey instruments in Appendix A and Appendix B). Descriptive statistics related to all measures can be found in Appendix C.

Independent Variables

Health Status. Health status was measured with a single item that asked patients to rate their current health as excellent, good, average, poor, or very poor.

Relational Closeness. Relational closeness was measured using a five-item scale based on measures of closeness developed by Vangelisti and Caughlin (1997) and later adapted for other studies (Ledbetter, 2009; Mazer & Thompson, 2011). Patients and surrogates were asked to agree or disagree on a 5-point Likert-type scale with statements such as “My relationship with the patient is close,” and “I consider my surrogate when making important decisions. When this survey was posted on Qualtrics, piped text was used to replace “patient” and “surrogate” with

each of the names of the responding dyad to help avoid any confusion. Reliability of this scale for both patients (α=0.796) and surrogates (α=0.891) was acceptable.

Openness about Death. Openness about death was measured using an adapted version of Mesters and colleagues' (1997) Openness to Communicate about Cancer in the Nuclear Family scale. The scale is altered so that participants report their partner's openness about death rather than cancer in 7 Likert-scaled questions. Questions include "My surrogate decision-maker doesn't like me to talk about death with them," and "Talking about emotions related to death upsets my surrogate decision-maker." In the surrogate decision-maker version of the survey these questions are altered to ask about the patient. When this survey was posted on Qualtrics, piped text was used to replace "patient" and "surrogate" with each of the names of the responding dyad to help avoid any confusion. This scale was adapted to include three measures of openness about death, which are derived from Goldsmith and Domann-Scholz (2013). They include talk about the spiritual, physical, and emotional aspects of death. The openness measure showed good reliability for both patients (α=0.797) and surrogates (α=0.891).

Short-Form Family Communication Patterns Scale. Family Communication Patterns Theory (FCPT) examines the long-established patterns of communication families engage in (Koerner et al., 2006). This measure includes an assessment of conformity- and conversation-orientation, the levels to which families seek mutual agreement and consensus and the levels to which families engage in open conversation and challenge one another's ideas, respectively. This study uses a shortened form of the original scale, as well as a number of new questions that have subsequently been tested. The original FCPT scale was shortened based on exploratory and confirmatory factor analysis of previous testing with respondents over 40 (See Appendix D). Items dealing with both conformity and conversation orientations were tested, and the final scale

includes 9 conversation items and 6 conformity orientation items. Additionally, 6 newly tested "warm conformity" items were added. These items assess the family's need to have strong attachments, spend time together, and share in traditions (Hesse, Rauscher, Goodman, & Couvrette, 2017). The 9-item conversation scale showed good reliability for patients (α=0.797) and moderate reliability for surrogates (α=0.684). The 6-item conformity scale showed excellent reliability for patients (α=0.955) and for surrogates (α=0.926). The 6-item warm conformity scale showed moderate reliability for both patients (α=0.657) and surrogates (α=0.743).

Communication Self-Efficacy. Self-efficacy is a measure of the perceived ability to engage in a particular behavior (Bandura, 1997). Although self-efficacy takes on many different forms and can include a number of different components, this study is focused primarily on both patients' and surrogates' confidence in their ability to talk with one another about end-of-life care, their communication self-efficacy. The measure of communication self-efficacy used here is adapted from the PEPPI, which in part measures a patient's self-efficacy with regard to communicating with health care providers (Maly, Frank, Marshall, DiMatteo, & Reuben, 1998). This validated measure was adapted to include 6 Likert-type questions that measure the individual's confidence in their ability to initiate conversations and to express end-of-life care goals. For patients, self-efficacy included confidence in their ability to communicate with a surrogate decision-maker or a physician, and for surrogates, self-efficacy included confidence in their ability to convey the patient's wishes to a physician. The adapted measures include the spiritual, physical, and emotional aspects of end-of-life care (Goldsmith & Domann-Schultz, 2013). The 5-item self-efficacy scale showed good reliability for patients (α=0.774), and surrogates (α=0.784).

Outcome Variables

End-of-Life Care Goals. Preferences for end-of-life care were assessed using an altered version of Karel and colleagues' (2007) Health Care Values Survey. This 13-item survey includes Likert-scaled questions that assess patient preferences, values, and goals. Only 5 items of this measure were used, with each representing a single-item measure. Each of the items used assesses a different dimension of end-of-life care designed to gauge the respondent's goals, wishes, and tolerances. Questions include whether the patient would want to live if they could not appreciate simple pleasures or if they could not feed themselves, whether they are worried about being a burden to family, where they wish to receive end-of-life care, their desire for pain medication, and their preference for who makes major decisions about their care. Items used 5-point Likert scale indicating their level of agreement with the statement.

Attitudes Toward Advance Care Planning. Attitudes toward advance care planning were assessed using a measure of attitudes toward the importance of advance care planning and reasons to engage in it as well as reasons not to engage in it. (Lai, Mudri, Chinna, & Othman, 2016). The original instrument contains 25 items, but it was shortened to include 9 statements with which respondents could agree or disagree, 3 of which are reasons for engaging in advance care planning, and 6 of which assess reasons for not engaging in advance care planning. To determine the extent to which patients engaged in advance care planning, 3 questions were asked before this measure was introduced. Patients and surrogates were asked whether the patient had talked to the surrogate about their end-of-life care, whether the patient had recorded their preferences on paper, audio, or video, and whether the patient and discussed end-of-life care with their physician.

If patients answered yes to any of the first three questions, then they were given 3 statements that identify specific motives for engaging in advance care planning, with a 5-point

Likert scale indicating their level of agreement with the statement. These statements included "I want to be able to make my own decisions" and "There may be differences of opinion about my care among my family members." If they answered no to all of the 3 pre-measure questions, they were directed to 6 single-item measures, which were statements that include motives for not participating in advance care planning, and they are asked to rate their level of agreement. These items included statements such as "I cannot imagine my end-of-life care" and "I feel that it is best to leave my future to fate or a higher power."

Surrogate Decision-Making Preferences. Surrogate decision-making preferences were measured using a 5-item assessment derived from a qualitative study of how surrogate decision-makers characterize their responsibilities (Vig, Taylor, Starks, Hopley, & Fryer-Edwards, 2006). The study found that surrogate decision-makers provided a range of ideas about the way surrogate decision-makers should make decisions, and those ideas could be characterized in 5 ways. These 5 ideas, such as "surrogates should make decisions based on past conversations with the patient," were formulated into statements to which patients and surrogates can indicate their level of agreement using a 5-point Likert-type scale.

End-of-Life Communication Priorities. The final measure included in this study is a measure of end-of-life care communication priorities. This measure is used as another check on concordance between the patient and the surrogate. In this scale, respondents were provided with 6 items that state a documented concern surrogate decision-makers express (Bruce et al., 2016; Bute, Petronio, & Torke, 2015; Torke et al., 2014). These items include statements such as "How much a treatment would cost" and "How painful a treatment would be." Respondents were asked to place the numbers 1, 2, and 3 by the concerns they consider the first-, second-, and third-most

important issues for the surrogate to discuss with physicians. Surrogates were asked to rank the concerns in the order the patient would want them to address the concerns with their physician.

Analysis

The primary analytical techniques used in these analyses were multilevel modeling and hierarchical linear regression. All tests were run in SPSS 23. Techniques used to achieve results for each aim are discussed in detail in the section below.

Results

Descriptive Statistics

A total of 144 participants completed the patient survey; however, only 78 recruited surrogates who completed the survey. Because concordance between patient and surrogate is the outcome measure for these analyses, only complete patient-surrogate pairs were analyzed; thus the number of patient-surrogate dyads analyzed in this study is 78. The pairs were asked to identify their relationship in terms of their structural roles in the relationship (Koerner & Fitzpatrick, 2002a). The majority described their relationship as spouse or romantic partner (n=60, 76.9%). Other pairs identified as having a parent-child relationship (n=12, 15.4%), a sibling relationship (n=2, 2.6%), an aunt/uncle-niece/nephew relationship (n=1, 1.3%), and close friends (3, 3.8%). The mean age of patients was 63 years old, with the youngest participant at age 55 and the oldest at age 82. The mean age of surrogates was 57, with the youngest participant at age 30 and the oldest at age 70. The frequencies of additional participant demographics for both patients and surrogates can be found in Table 1.

Table 1

Patient and Surrogate Characteristics

Characteristic	Patient (n=78)	Surrogate (n=78)
Health status		
Excellent	23 (29.5%)	
Good	21 (26.9%)	
Average	19 (24.4%)	
Fair	15 (19.2%)	
Poor	0	
Gender		
Male	29 (37.2%)	39 (50%)
Female	49 (62.8%)	39 (50%)
Ethnicity		
White	59 (75.6%)	55 (70.5%)
African-American	1 (1.3%)	1 (1.3%)
Hispanic	18 (23.1%)	22 (28.2%)
Income		
$25,000-$49,999	24 (30.8%)	21 (26.9%)
$50,000-$99,999	28 (35.9%)	21 (26.9%)
Over $100,000	26 (33.3%)	33 (42.3%)
Distance from Surrogate		
Less than 10 miles	60 (76.9%)	
11-50 miles	8 (10.3%)	
51-200 miles	4 (5.1%)	
Over 200 miles	6 (7.7%)	
Children Under 18 Living at Home		
1		21 (26.9%)
2		21 (26.9%)
3		33 (42.3%)

Results for Aim 1

Aim 1: Describe the degree of concordance between patients' and surrogates' assessments end-of-life care preferences, attitudes toward advance care planning, end-of-life care priorities, and surrogate decision-making preferences.

Results for the first three research questions in Aim 1 include two analyses: a comparison of mean scores across scale items for patients and surrogates, and a calculation of the concordance between patient and surrogates across items.

Comparison of means. Mean scores were compared using paired t-tests. The significance of comparing means in this context is to show a relative pattern in patient and surrogate scores. This pattern shows whether patients or surrogates systematically rated some items as more important than others.

Calculating Concordance. Concordance was calculated the same way for the measures of patient attitudes toward advance care planning, patient end-of-life care goals, and surrogate decision-making preferences. As done in previous studies, Likert-type items were simplified to calculate concordance (Desharnais et al., 2007). To simplify the concordance calculation, responses to each scale were recoded so that there were three possible answers. The answers "agree" and "strongly agree" were combined into "agreement," "neutral" remained the same, and "disagree" and "strongly disagree" were combined into "disagreement" so that there were three possible answers for each question. For each item, the variation of scores between pairs was assessed using Cohen's Kappa. Kappa is a measure of absolute agreement and is used here as an indication of the level of concordance between patient and surrogate responses across the entire sample (McHugh, 2012). However, because of the skewness of the some scales, the Kappa measure is difficult to interpret. Thus, Guilford's G, a measure of agreement that adjusts for such

skewness, was also calculated for those scales (Xu & Lorber, 2014). Results are discussed with the research questions below.

RQ1: What is the level of concordance between patient and surrogate global assessments of patient end-of-life care goals?

The end-of-life care preferences scale measured the importance of some elements of quality of life during end-of-life care. The scale asked for the respondent to assess the importance of doing things such as eating food to the patient's quality of life. For the patient end-of-life goals measures, there were no statistically significant mean differences between the scores of patients and surrogates across all of the items scored (see Table 2).

Table 2

Patient and Surrogate Means Comparison for End-of-Life Care Goals Using Paired T-Test

Item	Patient Mean	Surrogate Mean	Mean Difference	*P* value
Daily Activity	4.37	4.28	.09	.429
Food	4.23	4.27	.13	.382
Burden	4.31	3.79	.23	.764
Home	3.79	3.94	.14	.292
Pain	4.36	4.31	.05	.671

For the end-of-life care goals scale, tests for patient and surrogate concordance indicate no statistically significant, systematic agreement between patients and surrogates on any scale items. The percentage of patients and surrogates in agreement, as well as the Kappa and Guilford's G for the measure are reported in Table 3. The Guilford's G measure, an adjusted

version of Kappa, indicates agreement ranging from .03 to .4 for all measures, indicating slight agreement (Kenny, Kashy, Cook, & Simpson, 2006). Other testing was conducted to confirm these results, and McNemar-Bowker tests for agreement, which indicate whether there is evidence to argue against agreement in item measurement, although not reported here, indicated that these scale items showed statistically significant evidence *against* agreement (McHugh, 2012). An inspection of the descriptive statistics in Table 2 shows a trend in patients expressing agreement with most of the items, while surrogates ranked more of the items as neutral or disagree.

Table 3

Patient and Surrogate Percentage of Agreement on End-of-Life Care Goals and Kappa

Item	Percent Agreement	κ	*p*	Guilford's G
Daily Activity	78%	.04	.697	.32
Food	48%	.01	.779	.05
Burden	60%	.12	.155	.24
Home	31%	.10	.145	.03
Pain	78%	.00	.975	.40

RQ2: What is the level of concordance between patient and surrogate global assessments of patient attitudes toward advance care planning?

The attitudes toward advance care planning scale measured patient motives for either participating in advance care planning or not. Reasons included preserving decision-making

autonomy, sparing relatives the burden of making these decisions, and avoiding family conflict. Because only a small number of patients and surrogates answered the "not" questions (n=24) because of the logic of the survey, only the reasons "for" engaging in advance care planning are discussed below. For the patient attitudes toward advance care planning items, there were statistically significant mean differences between the scores of patients and surrogates across two of the items scored, the patient's desire to avoid family conflict and the patient's desire to avoid family burden (see Table 4).

Table 4

Patient and Surrogate Means Comparison for Attitudes Toward Advance Care Planning Using Paired T-Test

Item	Patient Mean	Surrogate Mean	Mean Difference	*p*-value
Preserve autonomy	2.89	2.87	.02	.784***
Avoid family conflict	2.62	2.32	.30	.008**
Avoid family burden	2.95	2.78	.22	.002**

Note: $*p < .05$, $**p < .01$, $***p < .001$

For the advance care planning attitudes scale, tests for patient and surrogate concordance indicate statistically significant agreement between patients and surrogates on all scale items (see Table 5). Statistically significant kappa scores can be interpreted based on their level of agreement. Kappa scores over .40 can be interpreted as indicating fair agreement, and kappa scores between .60 and .80 indicate moderate agreement (Kenny, Kashy, Cook, & Simpson, 2006; McHugh, 2012). The level of agreement for preserving autonomy and avoiding family

burden show moderate agreement between patient and surrogate, while the avoiding family conflict item showed only fair agreement (McHugh, 2012).

Table 5

Patient and Surrogate Percentage of Agreement on Attitudes Toward Advance Care Planning and Kappa

Item	Percent Agreement	κ	*p*
Preserve autonomy	76%	.46	.000***
Avoid family conflict	47%	.21	.010*
Avoid family burden	72%	.40	.000***

Note: $*p < .05$, $**p < .01$, $***p < .001$

RQ3: What is the level of concordance between patient and surrogate global assessments of patient surrogate decision-making preferences?

The surrogate decision-making preferences scale measured the ways in which patients and surrogates believe decisions for the patient's care should be made. The scale asked for the respondent to assess the importance of basing choices on conversations with the patient, the patient's legal documents, the surrogate's inner sense of what the patient would want, the surrogate's own values, and get help from other who know the patient's goals. For the patient end-of-life goals measures, there were statistically significant mean differences between the scores of patients and surrogates on the items measuring whether the patient should use his or her inner sense and whether the patient should rely on help from others (See Table 6).

Table 6

Patient and Surrogate Means Comparison for Surrogate Decision-Making Preferences Using Paired T-Test

Item	Patient Mean	Surrogate Mean	Mean Difference	*P* value
Conversation	4.21	4.32	.11	.346
Legal documents	4.70	4.49	.21	.150
Inner sense	4.61	4.31	.30	.034*
Own values	4.02	4.34	.32	.076*
Help from others	4.21	4.31	.10	.002**

Note: $*p < .05$, $**p < .01$, $***p < .001$

For the surrogate decision-making preferences scale, tests for patient and surrogate concordance indicate no statistically significant, systematic agreement between patients and surrogates on any scale items (see Table 7). Because of the skewness of the data, Guilford's G was also calculated for this scale. These measures range from .20 to .41 and indicate only slight agreement. Additional testing was conducted to confirm these results, and McNemar-Bowker tests for agreement, which indicate whether there is evidence to argue against agreement in item measurement, indicated that these scale items showed statistically significant evidence against agreement (McHugh, 2012). An inspection of the descriptive statistics below show variation across scale items. Surrogates appear to answer with greater agreement on the importance of conversation, reliance on legal documents, conversation with the patient, and conversation with others.

Table 7

Patient and Surrogate Percentage of Agreement for Surrogate Decision-Making Preferences and Kappa

Item	Percent Agreement	κ	*P*	Guilford's G
Conversation	81%	.01	.378	.34
Legal Documents	74%	.06	.495	.41
Inner Sense	59%	.10	.344	.23
Own Values	51%	.09	.324	.20
Talking to Others	67%	.13	.099	.30

RQ4: What is the level of concordance between patient and surrogate global assessments of patient end-of-life care priorities?

For the end-of-life communication priorities scale, concordance was calculated differently. Patients and surrogates chose the top three concerns that the patient would want expressed to their physician from a larger list of 6 items. Rather than calculating concordance by exact ranking (i.e., both patient and surrogate only reached concordance when listing the same priority statement ranked as their top priority), a very stringent calculation of concordance, a 3-point score for concordance was possible. Patients and surrogates earned one point for each concordant reason they chose. As seen in Table 8, over 75% of patients and surrogates chose two or more of the same reasons. The most frequent patient-surrogate matches were for the level of treatment success (n=54) and the likelihood of the treatment relieving symptoms (n=43). The least frequent match was cost (n=5).

Table 8

Frequency of Top Three Priority Matches

Item Matches	Frequency	Percentage
0	1	1.3
1	16	20.3
2	42	53.2
3	19	25.3

Results for Aim 2

Aim 2: Describe the effect of each dyad members' openness on measures of concordance.

Analysis of Openness about Death variable. Openness about death was measured on a 7-item scale with 5-point Likert-type items. Higher scores indicate stronger agreement with statements, and thus, more perceived openness. Scores for patients and surrogates had a minimum of 10 and a maximum of 31. For patients, the mean score was 22.36, with a standard deviation of 5.59. For surrogates, the mean score was 22.51, with a standard deviation of 6.52, indicating larger variation in the scores for surrogates than for patients. Bivariate correlation initially confirmed the non-independence of patient and surrogate responses, r=.55, p=0.000.[1]

As noted in the literature review, openness is a construct that is multi-dimensional (Goldsmith & Domann-Scholz, 2013). Thus, an initial inquiry was made into the similarity of ratings across items in the scale using intra-class correlation coefficients. Intra-class correlation

[1] Because of the finding of non-independence of the openness variable, actor-partner interdependence models were run to test for the possible partner effects on specific advance care planning variables that were tested for concordance. No partner effects were found; thus, separate regression models were created for openness. A possible explanation for the finding of no partner effects is that correlation does not account for systematic differences among means.

coefficients (ICC) are preferred in this context because the measure of interest is continuous, and ICCs can provide an assessment of similarity, as opposed to other measurements of correlation, which are not able to account for systematic differences within dyads (Kenny et al., 2006). Table 9 shows the intra-class correlations for the seven items of the survey measure.

Table 9

Analysis of Openness About Death Items

Openness about Death Item	Intra-class Correlation	Confidence Interval	*p*-value
I am mostly the one who starts conversations with _____ about death and dying.	.36	.15, .53	0.001**
I do not often talk about death and dying with _____.	.46	.27, .62	0.000***
My conversations with _____ about dying are usually brief.	.07	-.16, .29	0.270
Talking about emotions related to death and dying upsets _____.	.67	.52, .77	0.000***
Talking about what happens physically during death and dying upsets _____.	.57	.40, .70	0.000***
Talking about potential pain and suffering related to death and dying upsets _____.	.38	.17, .55	0.000***
Talking about spiritual questions related to death and dying upsets _____.	.56	.39, .70	0.000***

Note: $*p < .05$, $**p < .01$, $***p < .001$

Table 9 shows that similarity varies across items in the openness measure. The item for each dyad member's assessment of the how brief the conversations are does not show agreement.

All other items show agreement, with intra-class correlations ranging from .38 to .67. The strongest is 0.67, for the assessment of whether talking about emotions related to death upsets the other member. These findings of agreement are noted here because these items asked patient and surrogate to assess *one another*. The purpose was not to assess the patient's openness alone; thus, these measures of agreement indicate similarity in the way patients and surrogates assess one another.

Concordance score calculation. For each of the measures of concordance named above, a percentage of concordance was calculated. Because each metric had a different number of items, this percentage allowed for analysis across metrics, as well as a mean calculated concordance score. The summary statistics for concordance scores as percentages are reported in Table 10 below.

Table 10

Concordance Measures by Percentage

Concordance Measure	Mean	Standard Deviation
Patient Preferences for End-of-Life Care	.66	.25
Patient Goals for End-of-Life Care	.55	.22
Patient Attitudes Toward Advance Care Planning	.34	.21
Attitudes Toward Surrogate Decision-Making	.64	.27

Openness as a Predictor of Concordance. Before models using the openness measure to predict concordance were run, all other independent variables were tested for inclusion in the model using bivariate correlations. Table 11 presents correlated independent variables, patient

and surrogate including openness. The variable "age gap" is the difference between the patient's and surrogate's ages, and "gender concordance" is the match between patient and surrogate gender. All independent variables (including self-efficacy, closeness, and health status) were tested with both bivariate correlations and linear regression models, but only those that correlated with at least one measure of concordance are reported below.

Table 11

Correlation Table of Independent Variables with Concordance Measures

Measure	Preferences Concordance (*p*)	Goals Concordance (*p*)	Attitudes toward Advance Care Planning (*p*)	Attitudes toward Surrogate Decision Making (*p*)
Patient Openness	.13	.31**	.31*	.31**
Surrogate Openness	-.03	-.03	-.16	.18
Age Gap	-.26*	-.17	-.10	-.14
Gender Concordance	.03	-.16	-.05	.01
Patient Health Status	-.23*	-.18	.06	-.24*
Patient Closeness	-.23*	-.09	-.05	-.21
Surrogate Closeness	-.13	-.04	-.26*	-.07
Race	.23*	-.13	-.05	.41***

Note: $*p < .05$, $**p < .01$, ***p < .001

For the research questions below, hierarchical linear regressions were performed with openness as the first predictor to test the independent and combined effects of openness and

covariates. Models were fitted using change in R^2 balanced against changes in collinearity tolerance statistics. Interaction effects that were not statistically significant are not reported in the tables below.

Because the outcome variables are percentages, and potentially not a good fit for linear regression, normality of the error terms was tested graphically for the models to ensure that this basic assumption of linear regression was not violated. Models using surrogate openness about death were tested for each concordance variable. None yielded statistically significant results for the relationship between surrogate openness and concordance. Thus, those models are not reported here.

RQ5: Do patient and surrogate assessments of one another's openness about death and dying predict concordance between patient and surrogate global assessments of patient end-of-life care goals?

Table 12 shows the coefficients for the regression model using patient openness to predict patient end-of-life care goals. Patient openness is negatively related to concordance in predicting patient end-of-life care goals when controlling for effect of the age gap between the patient and gender concordance. Age gap and gender concordance are also negatively related to concordance in patient end-of-life care goals.

Table 12

Openness Predicting Concordance in Patient End-of-Life Care Goals

Variable	Beta	Standardized Beta	Standard Error	*P*
Patient Openness	.20	.56	.00	.000***
Age Gap	-.01	-.28	.00	.000***
Gender Concordance	-.07	-.13	.06	.015*

Patient Health	-.05	-.29	.02	.231

Model fit statistics (R^2=.47, F(1,74)=7.42, p=.008**)

Note: *p < .05, **p < .01, ***p < .001

RQ6: Do patient and surrogate assessments of one another's openness about death and dying predict concordance between patient and surrogate global assessments of patient attitudes toward advance care planning?

Table 13 shows the coefficients for the regression model using patient openness to predict patient attitudes toward advance care planning. Patient openness is negatively related to concordance in predicting patient attitudes toward advance care planning when controlling for the age gap between the patient and gender concordance. Age gap and gender concordance are also negatively related to concordance in patient attitudes toward advance care planning.

Table 13

Openness Predicting Concordance in Patient Attitudes Toward Advance Care Planning

Variable	Beta	Standardized Beta	Standard Error	*P*
Patient Openness	.14	.44	.00	.001**
Age Gap	-.02	-.25	.00	.048**
Gender Concordance	-.27	-.61	.06	.050**
Patient Health	-.01	-.02	.02	.625

Model fit statistics (R^2=.404, F(1,74)=5.589, p=.021*)

Note: *p < .05, **p < .01, ***p < .001

RQ7: Do patient and surrogate assessments of one another's openness about death and dying predict concordance between patient and surrogate global assessments of patient surrogate decision-making preferences?

Table 14 shows the coefficients for the regression model using patient openness to predict patient preferences for surrogate decision making. Patient openness is positively related to concordance in predicting patient surrogate decision-making preferences when controlling for the age gap between the patient and gender concordance. Age gap and gender concordance are also negatively related to concordance in patient surrogate decision-making goals.

Table 14

Openness Predicting Concordance in Patient Surrogate Decision-Making Preferences

Variable	Beta	Standardized Beta	Standard Error	*P*
Patient Openness	.01	.26	.00	.042*
Age Gap	-.08	-.22	.00	.299
Gender Concordance	.01	.25	.06	.168
Patient Health	-.04	-.16	.02	.697

Model fit statistics (R^2=.126, F(1,74)=2.677, p=.038*)

Note: *$p < .05$, **$p < .01$, ***$p < .001$

RQ8: Do patient and surrogate assessments of one another's openness about death and dying predict concordance between patient and surrogate global assessments of patient end-of-life care priorities?

Table 15 shows the coefficients for the regression model using patient openness to predict patient and surrogate concordance on patient end-of-life care priorities. Patient openness does not have a statistically significant relationship to concordance, but the age gap between patients and surrogates did have statistically significant negative relationship to concordance between patient and surrogate about patient end-of-life care priorities, meaning that a larger age gap predicted less mean concordance, holding other variables constant.

Table 15

Openness Predicting Concordance in Patient End-of-Life Care Priorities

Variable	Beta	Standardized Beta	Standard Error	*P*
Patient Openness	.13	.05	.00	.923
Age Gap	-.01	-.30	.21	.021**
Gender Concordance	.11	.19	.07	.129
Patient Health	-.01	-.03	.02	.099

Model fit statistics (R^2=.233, F(1,74)=2.790, p=.049**).

Note: *p < .05, **p < .01, ***p < .001

Results for Aim 3

Aim 3: Examine the relationship between Family Communication Patterns and concordance.

Classifying families. Before analysis of these hypotheses took place, patient-surrogate pairs were classified by family type according to Family Communication Patterns Theory. This classification was done as described by previous literature, plotting the mean conversation orientation score for patients and surrogates against the mean conformity scores of patients and

surrogates (Hamon & Schrodt, 2012; Koerner & Fitzpatrick, 2002b). One methodological challenge to creating this classification that Koerner (2002) discusses is considering disparate ratings of conversation orientation and conformity orientation based on family role. Koerner (2002) suggests that these effects can be controlled for using a *z*-test. The problem with this data is that the definition of family was broad, and the choices for identifying individual role in the family (mother, father, etc.) in the survey were not such that every participant could be characterized based on past literature. This analysis has proceeded despite this limitation, however, because first, the discrepancies noticed were not large across the sample (largest discrepancy was 5 points for conversation orientation), and second, this study argues that patients and surrogates take on different family "roles" with regard to the patient's end-of-life care, so their assessments based on traditional family roles does not bear as much on this analysis. By plotting conversation orientation against conformity orientation all 78 patient-surrogate pairs were categorized. There are 9 consensual families, 25 protective families, 37 pluralistic families, and 7 laissez faire families.

To complete these analyses, ANCOVAs were set up for each of the four concordance scores. Based on the results of correlation analysis and single-variable regression analysis for covariates, gender concordance was used as a random factor in each of these analyses.

H1: Patient and surrogate family communication environment type will influence patient and surrogate concordance on patient end-of-life care preferences.

Patient and surrogate family communication type did not have a statistically significant effect on concordance on patient end-of-life care preferences $F(3, 77) = .427$, $p = .788$, $\eta^2 = .03$.

H2: Patient and surrogate family communication environment type will influence surrogate concordance on patient attitudes toward advance care planning.

Patient and surrogate family communication type did have a statistically significant effect on concordance on patient attitudes toward advance care planning F(3, 77) =2.763, p=.000, η^2 = .09. There was a statistically significant difference between pluralistic families (n=37) and protective families (n=25). Pluralistic families scored, on average, 12% higher on concordance between patient and surrogates on patient attitudes toward advance care planning than laissez-faire and consensual families (p=.043).

H3: Patient and surrogate family communication environment type influence patient and surrogate concordance on patient surrogate decision-making preferences.

Patient and surrogate family communication type did have a statistically significant effect on concordance F(3, 77) =3.868, p=.013, η^2 = .25. There was a statistically significant difference between pluralistic families (n=37) and laissez-faire families (n=7), as well as a statistically significant difference between protective families (n=25) and laissez-faire families (n=7). Pluralistic families scored, on average 20% higher on concordance between patient and surrogates on patient attitudes surrogate decision-making preferences than laissez-faire families (p=.049). Protective families scored on average 30% higher on concordance between patient and surrogates on patient attitudes surrogate decision-making preferences than laissez-faire families (p=.017).

H4: Patient and surrogate family communication environment type will influence patient and surrogate concordance on patient end-of-life care goals.

Patient and surrogate family communication type did not have a statistically significant effect on concordance on patient end-of-life care goals F(3, 72) =.192, p=.585, η^2 = .06.

Discussion

The results for Aim 1 show that patient and surrogate concordance about patient preferences for their end-of-life care were fair to good for attitudes toward advance care planning and patient priorities for advance care planning, while concordance was lacking for surrogate decision-making preferences and patient end-of-life care goals. These results make the important point that patients and caregivers may differ in the way they want end-of-life care decisions to be made, and they may lack understanding of the core issues of importance to the patient in their end-of-life care. Sudore et al. (2010) refer to the notion of granting "leeway" to a surrogate decision maker, giving that person either more rigid instructions to interpret the patient's wishes, or giving a surrogate decision maker more room to assert their own judgment. These results also indicate that surrogates may differ in core assumptions about the way decisions should be made for patients, and discussion of leeway is an important way to come to an understanding of how the surrogate should make decisions. The problem with a lack of surrogate and patient concordance on patient goals for end-of-life care is troubling, but speaks to the problem of uncertainty in early advance care planning. More work should be done to address goal concordance, for it is an important measure by which surrogates make decisions for patients (Shalowitz et al., 2006; Vig, Starks, Taylor, Hopley, & Fryer-Edwards, 2007).

The results for Aim 2 show statistically significant relationships between patient perceptions of surrogate openness about death on concordance across three measures. Because the measure is one of perceived openness about death in which the patient assessed how willing the surrogate was to talk about death, this result suggests that the level of openness about death that a patient perceives in his or her surrogate decision maker is a factor in patient-surrogate concordance. While interventions currently focus on patient openness, this result indicates that a shift in thinking might be necessary. Interventions focused on surrogate openness to addressing

these issues may be warranted. Additional work should be done to test openness across patient-surrogate relationships, such as spouse and parent-child because differences in relationship type may carry with them different levels of openness.

The results of Aim 3 make a very important suggestion about the relationship between family communication environments and concordance. Taken together, the results from the hypotheses suggest that pluralistic families engage in some communication and decision-making behavior that leads to greater concordance than other family communication environment types. This result provides quantitative support for Wittenberg-Lyles, et al. (2012), who observed that pluralistic families tend to engage in more talk that facilitates end-of-life caregiving. The results also provide support that both pluralistic and protective families might also engage in some behaviors, or they have some patterns of decision-making that facilitate concordance on end-of-life care decision-making.

Theoretical Implications

This study first makes a meaningful connection between open communication about death and dying and concordance, as well as a connection between family communication environments and concordance. While much research has examined the causes of concordance and discordance, none has connected it to communication behaviors and family communication habits. It also solidifies a link between family communication and decision-making. This is an important connection, as most literature involving advance care planning, and concordance in particular, situates advance care planning in a healthcare environment exclusively and not a family communication environment. Family communication environments are the places in which many people spend much more time than in healthcare settings. Thus, these environments

merit more attention and study in terms of how they impact patients' and surrogates' abilities to reach concordance on patients' goals and preferences for decision making.

Second, this study provides the foundation for an argument that decision-making preferences, specifically in an advance care planning context, are related to deeply held family communication patterns and the environments those patterns create. Although decision-making preferences have been discussed with regard to Family Communication Patterns Theory, work in this area has yet to offer a concomitant decision-making typology. This theoretical and practical link could be used to both inform decision science theories and to enrich the study of family communication environments.

Practical Implications

By more clearly elucidating the relationship among family communication, openness, and concordance with patient wishes, this study underscores the need for family-based advance care planning interventions. These interventions should be aimed at helping families create open conversation about death and dying, as well as specific end-of-life care preferences. Additionally, the discovery of a relationship between family communication patterns and surrogate decision-making preferences could have interesting implications for interventions regarding advance care planning and beyond. Items in the surrogate-decision-making preferences scale assessed preferences for decision-making by surrogates that correspond to a substituted-judgment standard in which surrogates do their best to decide in the same way a patient would for their own care, while a best interests standard relies on the surrogate exercising their own judgment under the circumstances. Knowing that some families might favor a substituted judgment standard versus a best interest standard could encourage more meaningful conversation around how end-of-life care decisions are made.

Limitations and Future Directions

This study has several limitations involving the sample. The sample was drawn from internet users, who tend to be wealthier and better educated than most. The sample also lacks in racial diversity. A more socio-economically and racially diverse sample could show different results, given the relationship among income, race, and a lack of advance care planning. The sample size is also relatively small. A larger sample would also help achieve the power required for more sophisticated statistical tests, making conclusions more generalizable. This is particularly true for the Family Communication Patterns classification of family communication environment types, in which the types ranged in size from 7 families to 37 families. Future work with this data should be aimed at collecting larger numbers of families that fit in the consensual family type and the laissez-faire family type.

A final lingering question raised by these results is the connection between the concordance measures and concordant end-of-life care decision-making. The connection between early advance care planning and concordant care should be examined. Finally, because this survey was completed online, it is unclear whether patients and surrogates ever have or will engage in advance care planning. One possible redesign for this study would be to have surrogates and patients take the survey in close proximity and compare results to spark open conversation about advance care planning.

Conclusion

This study has established an important link among communication variables and advance care planning. It underscores the need for further work to cross the boundaries of the clinical environment and the family environment to consider the importance of family communication patterns and behaviors such as open conversation. This work is important for

creating interventions and policies that will help patients and their families get end-of-life care that is meets her wishes.

CHAPTER IV

STUDY TWO

REAL TALK ABOUT DEATH AND AN EXTENDED TYPOLOGY OF FAMILY COMMUNICATION PATTERNS IN ADVANCE CARE PLANNING DECISION-MAKING

Research Questions and Rationale

The family microsystem presents unique challenges to conversations involving advance care planning. Because families create distinctive communication environments in which these conversations take place, studying what happens when families discuss advance care planning in their home environment offers an opportunity to characterize those conversations in that environment (Ritchie & Fitzpatrick, 1990; Scott & Caughlin, 2015). The overarching goals of Study Two, then, are to describe the what people talk about when they discuss advance care planning in a family context and to identify characteristics of family communication environments that influence the decision-making styles, attitudes toward advance care planning, and communication behaviors related to advance care planning.

Decision-making for end-of-life care can cause emotional strain and tension, and advance care planning offers an opportunity to anticipate conflicts and to discuss the ways decisions will be made (Kramer et al., 2009). Engagement in advance care planning has been shown to improve healthcare outcomes and to ease survivors' grief (Kass-Bartelmes & Hughes, 2004; Prendergast, 2001). But there is some debate over what precisely individuals can and should discuss (Pearlman et al., 1995; Porensky & Carpenter, 2008). Traditional thinking has held that patients and surrogates should use legal documents as prompts for discussing advance care planning,

including advance directives that specify end-of-life care wishes and medical powers of attorney, which designate a decision-maker in the case of incapacity (Association, 2005). However, more recent work has held that patients should focus not only on who will make decisions for them, but also how much leeway those decision makers should have in making healthcare decisions, and how they define quality of life (Sudore et al., 2017; Sudore et al., 2015). Talking about an individual's death is the common thread in all these discussions.

But questions of how individuals and their surrogates really talk when they examine the notion of making end-of-life care decisions and what sort of topics they bring up during that discussion have not been addressed. It is notoriously difficult, if not impossible, for patients and family members to project themselves into an unknown future so that they are able to make realistic decisions about the circumstances of their death (Leventhal, Jessica, Leventhal, & Bodnar-Deren, 2016). Death is a difficult subject at best, and a completely taboo subject at worst (Silveira et al., 2000). Cultural practices, personal beliefs, and emotions all color an individual's ability to talk about their mortality (Templer, Ruff, & Franks, 1971).

Using ideas such as terror management theory, some even argue that individuals go to great lengths to avoid contemplating their mortality, and individuals are hard-wired to avoid the subject (Buss, 1997; Navarrete & Fessler, 2005). But advance care planning has become a national priority, and more than ever, people are encouraged to contemplate the circumstances of their end-of-life care (Prendergast, 2001). But when asked to make decisions that anticipate the circumstances of a patient's end-of-life care, both patients and surrogates often focus on specific treatments and not on patient goals and preferences (Sudore & Fried, 2010). Thus the question remains—even though people know intellectually that they will die, why do they have such a

difficult time imagining those circumstances? With this paradox in mind, this study first asks the following research question:

RQ1: How do patients and their family surrogate decision makers talk about death when they are asked to discuss hypothetical scenarios involving end-of-life care decisions?

A second consideration in this study is how the communication environment in different family microsystems shapes these conversations. Advance care planning involves high levels of radical uncertainty, a situation in which the possibilities are so numerous and the outcomes so remote that they are impossible to grapple with using the decision-making calculus that most people use every day (Tuckett & Nikolic, 2017). This uncertainty involves medical, spiritual, practical, and psychosocial elements (Brashers, Goldsmith, & Hsieh, 2002). There is a prevailing assumption that uncertainty in advance care planning is reducible through effective family and physician communication; however, there is scant evidence that even in the most functional of communication environments, uncertainties related to disease, death, and dying can be effectively managed (Hines, 2001). There is, however, some research suggesting that families who are better able to manage and cope with uncertainty are the one who are better able to better communicate this uncertainty among family members and to cope with it (Moorman & Carr, 2008).

In addition to navigating this uncertainty, families must also manage the conflict that occurs. Conflict in this decision-making context has been linked to family relationships, roles, and individual differences in coping skills (Parks et al., 2011; Kramer, Boelk, & Auer, 2006). Family members sometimes offer differing ethical and moral perspectives on end-of-life care, as well as differing spiritual convictions (Bowman, 2000). Family communication patterns have been linked with differences in conflict management skills and can often predict behaviors and

attitudes (Schrodt et al., 2008). Although these skills have been linked to family communication patterns for hospice caregivers, they have not been described for family members engaging in advance care planning (Wittenberg-Lyles et al., 2012). Thus this study poses a second question:

RQ2: How can family communication microsystems be characterized in an effort to describe members' collective management of uncertainty and potential for decision-making conflict in advance care planning?

Methods

Participants

A total of 19 pairs of seniors and their surrogate healthcare decision makers were recruited for this study. Participants for this study were individuals over 60 ("patients") and their primary healthcare surrogate decision maker who is also a family member. In the recruitment materials, "family member" and "surrogate healthcare decision maker" were defined using current literature. In an effort to be as inclusive as possible of different family structures, the materials defined a family member as "someone with whom you share intimate, strong ties and a sense of commitment; this person does not necessarily have to be related to you by blood or marriage." This definition was written to comport with the transactional model of family, which holds that given the fluidity of family structures, family can be defined as a group of intimates that share a set of experiences (Koerner & Fitzpatrick, 2002a; Noller & Fitzpatrick, 1993). Surrogate health care decision maker was defined as "the person who will make decisions for your care when you can no longer do so," which is a simplified version of the legal definition (Fritch et al., 2013).

Among the pairs included in the study, 15 (79%) described themselves as having husband-wife or romantic partner relationship, and the rest described themselves as having a

parent-child relationship 4 (21%). Participants were not asked their ages, but were asked to estimate their age gap, the difference between the patient and surrogates' ages. The majority of the husband-wife pairs described being within 10 years of one another, while the parent-child pairs had age gaps ranging from 20 to 35 years.

Recruitment

Participants were recruited primarily through the Houston-Galveston Area Council on Aging. The Agency runs multiple programs for seniors 60 and over, as well as their families and caregivers, throughout the Houston area. Among the Agency's affiliated programs are senior centers throughout the area. The Agency contracts with community organizations to offer senior services such as physical fitness courses, educational programs, and benefits counseling. Most of these services are offered during regular hours at the senior centers, and the centers are described by some patrons as a "hangout" where some go daily to spend time.

Participants were recruited through fliers, email, and in-person recruitment at the centers. A unique feature of the senior centers under the Agency is that they offer a diverse sample of communities in the Houston area, including different socio-economic levels, races, religious preferences, and cultures. A comprehensive list of centers and activities supported by the Agency can be found at: http://www.h-gac.com/human-services/aging/senior-center-services.aspx. Once participants agreed to join the study and their surrogate decision maker was contacted, a location for the interview was chosen by the patient. The majority of interviews took place in the interviewees' homes, while 3 took place in quiet public spaces. Upon completion of their participation, each person was offered a $20 Amazon.com gift card.

Design

Participants were asked to both independently and collectively answer questions involving advance care planning. Patients and their surrogates were first asked to take digital recorders into separate, private spaces within the individual's home or the public space so that they could not hear one another's answers. They received three sheets, the first with questions and the others with a scenario and questions. These sheets were personalized for the pair using the patient's and surrogate's first names. Names were either entered on the computer or hand written in sheets prepared with blanks.

Both the surrogate and the patient first answered general questions about healthcare decision-making. Patients were asked how they made healthcare decisions, while surrogates were asked to describe how the patient made healthcare decisions for themselves. Questions also asked the patient and surrogate to describe the patient's goals for their end-of-life care and several questions about who else in the family the patient would rely upon to help with the decision-making.

Patients and surrogates then read a two-part scenario that asked them to imagine that the patient needed a feeding tube. In the first part of the scenario, the patient was very ill and could no longer feed themselves (see Appendix E for interview materials). The surrogate had to decide whether to have the feeding tube inserted or to be hand-fed. The scenario had the patient's doctor explain risks and benefits of the procedure to the surrogate. Both patients and surrogates were then asked what kind of information a surrogate would need to make the decision and what the patient would want. They were also asked to envision how these decisions would be made and to describe family barriers and opportunities they imagine during the decision-making process.

Once they answered these questions, the patient and surrogate read a second passage that was a continuation of the first scenario. In this case, the surrogate had opted for the feeding tube, but it was no longer working. The physician does not know why, but she has suggested that the feeding tube be either removed or replaced. Patients and surrogates then answered similar questions about what kind of information was needed, what the patient would want, and which family members would be helpful in making the decision under the new circumstances.

Following the individual recordings, both participants were asked to have a minimally structured conversation with the researcher. Prior to this conversation, the researcher explained that she would not ask participants to share any of their recorded information. Rather, the conversation was to be a guided dialogue intended to get participants to discuss their thoughts about making these decisions. Some of the scheduled topics included each member's confidence in the surrogate's ability to make decisions for the patient, anticipated family conflicts, and confidence in the fact that the patient's wishes would be carried out by family and physicians.

Finally, each participant was individually asked complete a post-conversation writing task (See the writing task in Appendix F). In the task, each participant was asked to assess the level of openness in the conversation, to describe whether this conversation fits into their "normal" family patterns of communication, and to share their feelings about the conversation. The writing task took around 5 minutes.

Analysis

Full transcriptions of the audio recordings, as well as writing task responses and field notes were used for analysis related to both research questions. Research question one involved an open, iterative approach to coding instances in which patients and surrogates discussed death (Tracy, 2012). Because people tend to talk about death indirectly, special attention was paid to

the use of metaphor, turn of phrase, and indirect references (Rodriguez et al., 2007). But what became most interesting over the course of this coding was the way individuals resisted talking about death with any depth. After careful review of the conversations, coding shifted to defining and categorizing strategies patients and surrogates used to avoid talking about the patient's death with any depth. These strategies served as barriers to continued conversation. Codes for these strategies were developed and refined iteratively. See Appendix G for the codebook for Study Two.

As the initial content analysis occurred, it also became clear that patients and surrogates engaged in storytelling when talking about death. Thus a secondary analysis aimed at identifying and examining the parts of and themes within these narratives began. Narrative analysis involves cataloging key manifest and latent features of the content (Hsieh & Shannon, 2005). Manifest features of family narratives examined in this study include plot, character, and themes related to patient death (Cullum-Swan & Manning, 1994; Macnamara, 2005) Thematic analysis involves piecing together the narrative elements to construct an overarching idea (Altheide & Schneider, 2012). This analysis included rethinking the placement of the narrative in the conversation, the main ideas the story represented, and any relational function the story might serve.

In the subsequent analysis for research question two, elements of the constant comparison method were first used, including an iterative coding scheme (Straus & Glaser, 1967). Content-related codes were developed by moving between the data in the transcripts and relevant literature involving advance care planning, including research involving designating surrogate decision makers, completing documents, and talking about death. While comparing the literature with the interactions, it became clear that previous work applying Family Communication Patterns (FCPT) in a qualitative context might be ideal for this analysis.

Goldsmith et al. (2012) used FCPT to frame their study of caregiver communication habits in an oncology setting. In the study described in Goldsmith et al. (2012), hospice patients and their caregivers were interviewed using questions from *a priori* categories established by the four specific family communication pattern types described in the literature: protective, consensual, laissez-faire, and pluralistic (Koerner et al., 2006). While this study did not employ such a framework in its interview technique, it became clear when comparing the categories discussed in Koerner et al. (2006) and the application to the hospice context that elements of the family communication pattern types were represented in the interviewees' responses. Thus a structure for coding was created based on a search of past research using these categories. Definitions of each category were synthesized, and examples from past studies were included in coding notes for reference.

Once the categories were created, transcripts were examined to develop themes related to each category of family communication, to pinpoint exemplars, and to characterize the patient and surrogate pairs' overall family communication type. Because this study was not designed to identify family communication patterns like the study of Goldsmith et al. (2012), pairs were not assigned a definitive classification. Rather, the question asked was whether elements of the pair's interaction appeared to fall into one category or another.

Results and Discussion

Research Question One: Talk about Death

True to the literature of terror management theory, talk about death largely involved participants explaining why no one wants to talk about it and why no one wants to get old enough to die. A man who revealed he was in his 80s casually described in an aside how he couldn't "imagine getting that old" when asked to think about how he would like decisions to be

made for his end-of-life care. While his joie de vivre is to be admired, his is a prominent example of a common resistance to thinking about end-of-life care. A surrogate, when asked why he did not want to talk about the patient's end of life care, described a common relative as living to be over 100 years old, so there was "a century" to wait and why talk about such an "unhappy subject?"

Another common idea was avoiding the subject for seemingly superstitious reasons. The underlying idea was that if a person talks about their own death, they will hasten it. One patient, who had a major health scare in the past two years said he didn't want to "tempt fate" when he was asked by his surrogate to talk about his end-of-life care. While he was the only participant who explicitly stated it, others hinted at the not wanting to "go too far" with thinking about end-of-life care, implying that there would be a point at which too much thinking, talking, or imagining might make something awful happen. A final surrogate summed his thoughts up with "when it happens, it happens. Enough with it."

A final common theme related to avoiding the topic was avoiding talking about death because of the itinerate indignities involved in a slow death. Surrogates and patients described a range of losses they did not want to face with regard to their autonomy, from not being able to "get" a conversation to not being able to "shower and get groceries" to not being able to take care of their family financially. One patient vividly described how she did not want to think about her husband having to "clean [stuff] out from under" her fingernails or "change [her] dirty diaper." She would rather "end it." Another surrogate explained that he could not imagine living with himself knowing his children had to bathe him and see his naked body. Discussion of these indignities frequently and surprisingly led to talk of suicide ("getting the shotgun") or assisted

suicide outside of a healthcare context ("I know [name of relative] would help me out of that one").

Although these pronouncements were not interpreted as serious threats in context, they point out an important characteristic of these three ways of talking about death. Discussion of each of these themes served to punctuate that episode of the conversation. That is, the statements described here had the effect of stopping the flow of the conversation and were a signal to move on to different subject matter, even if an interview partner or the interviewer appeared to want to continue talking about the subject. These instances are worth noting not only because they are emblematic of a resistance to engaging in talk about death across nearly all participants, but because these are conversational moves that may become prime targets for redirection. In the "shotgun" instance mentioned above, the researcher playfully asked, "Suicide instead of a hospital bed, huh?" The patient responded by saying vehemently he would never do such a thing, but the subject was too "hard" to think about. This represented a point at which the conversation could be redirected to talk about advance care planning, which could be a useful potential intervention strategy in this context.

Across all participants, patients and their surrogates told stories during the course of the conversation. Stories included ones about others' deaths, funerals, and health scares. As the narrative medicine school of study posits, narratives are powerful persuasive tools that influence individuals' perceptions and beliefs (Sharf et al., 2003). They provide ways to make sense of uncertain situations, to explain decision-making, and to infer values and judgments (Fisher, 1985; Sharf, 2016). Family narratives offer the added element of revealing family identity, member connectedness, and family culture (Metts & Lamb, 2006). Differences in telling these narratives can reveal family members' differing attitudes toward health, illness, and death

(Baider, 2008). Additionally, as Tuckett and Nikolic (2017) note, under circumstances such as advance care planning that involve so much uncertainty, narrative can help individuals understand problems, simulate future outcomes, gain social support, and articulate a preferred course of action.

Stories related to death that were told in the interviews appeared to accomplish some of those tasks. A first type of story was one told by patients to surrogates as an apparent cautionary tale that articulated an undesired course of action. These stories primarily involved bad decisions on the part of families in caring for a loved one and were told with emphasis on the perspective of the loved one. In these stories, patients emphasized the suffering or indignity faced by the subject of the story. One patient described an in-law who had been put on life support because his wife "just couldn't bring herself" to opt for palliative treatment alone. The patient described the way the in-law lingered, in apparent pain, for weeks, but was "forced to stay in that dead body." The last sentence underscores vividly the idea that the patient did not wish to suffer like the person in the story. This type of story could be read as an attempt to make concrete the patient's preference for the surrogate by way of illustration, even though it did not express a direct preference.

A second story type involved an element of social support. Some patients and surrogates described bad family actors who had the potential to impede on the patient's wishes playing out. Many pairs described having more distant family members who would cause "all hell [to] break loose" if they were involved in making decisions for the patient's care. For one patient, it was a pair of sisters who were more religious than him and would "make a stink" about his wishes because he only wanted palliative options only in the event he had a terminal illness. He accompanied this description of his sisters with a story about how the sisters worked to convince

their mother to send their father to the I.C.U. for intubation after an unsuccessful cancer surgery. The patient said his nuclear family should "take the lead" and not let the sisters be involved in decision making. The surrogate responded to this statement with a nod. The surrogate's response illustrated that these stories had the effect of bolstering family fidelity, as if to say, "I think you family members are the best ones to make the decision—stick together and ignore the others." This could be read as a move of social support, as if to affirm the patient's confidence in his family's decision-making ability.

A final type of storytelling dealt with potential outcomes of poor planning for death. Patients and surrogates both described instances of people making poor choices and not dying without taking care of their families first. These stories dealt with burdening the family with the disposition of remains, loss of income, and expensive treatment that the family was burdened with after the subject of the story died. In these stories the focus was on the family of the person who died and the fact that the deceased person had made choices that had a negative effect on the family. It should be noted that financial issues were mentioned in many of the conversations. In one story a cousin of the patient left his family so destitute that they had to cremate him despite their religious beliefs against it. In another, a family was paying medical bills long after a man's death after an experimental treatment, a burden that "tore them up." For patients, these stories appeared to bolster the patient's desire to show the surrogate that they were trying to make a good decision not just for themselves, but for the family by preparing for their end-of-life care. For surrogates, they helped to tell the patient that their engagement in advance care planning was a good thing.

Research Question Two: FCPT Typology

Family Communication Patterns Theory provides a specific way to characterize family communication environments. Using conversation orientation and conformity orientation as axes, families can be described in terms of their levels each variable as seen in Figure 3. The four types of family communication environments include protective, consensual, laissez-faire, and pluralistic (Koerner et al., 2006). These categories, which will be discussed in further detail in this analysis, have been used to describe the ways families avoid or embrace taboo subject matter, the way members behave toward one another, and how families negotiate conflict (Schrodt et al., 2008).

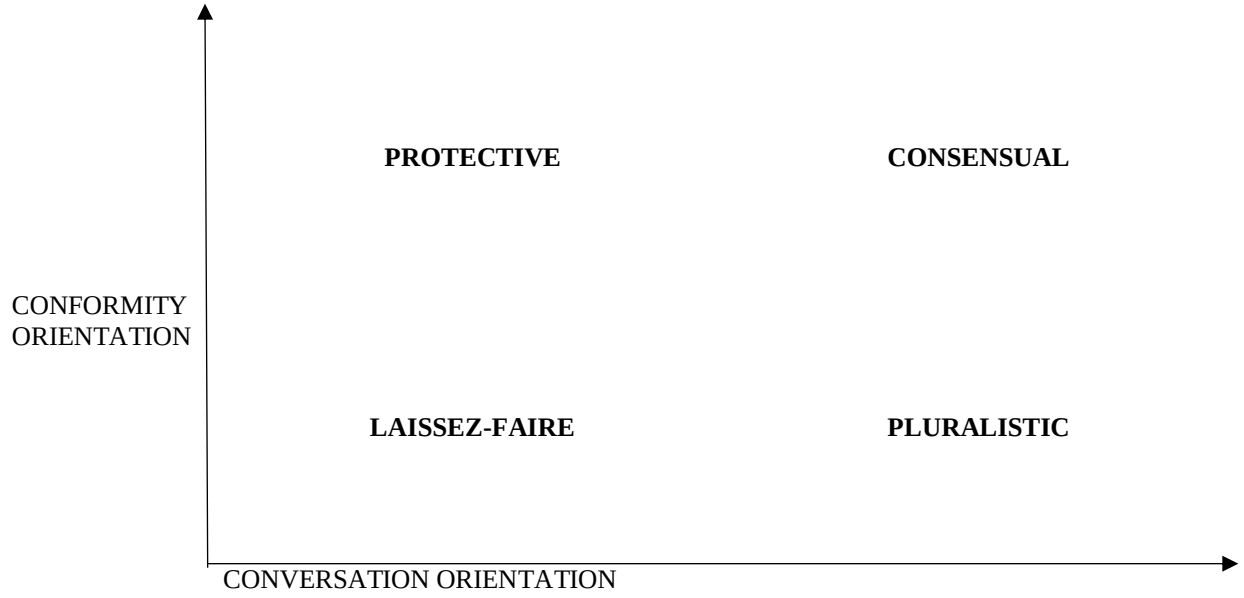

Figure 3. FCPT Family Types

The communication behaviors associated with levels of conversation and conformity orientation are of particular importance to advance care planning. Because decision-making for end-of-life care can cause emotional strain and tension, advance care planning offers an

opportunity to anticipate conflicts and to discuss the ways decisions will be made (Kramer et al., 2009). To complicate matters, family members offer differing ethical and moral perspectives on end-of-life care, as well as differing spiritual convictions (Bowman, 2000). Conflict in this decision-making context has been linked to family relationships, roles, and individual differences in coping skills (Parks et al., 2011; Kramer, Boelk, & Auer, 2006). Family communication patterns have been linked with differences in these skills and can often predict behaviors and attitudes (Schrodt et al., 2008).

Following the approach of Wittenberg-Lyles et al. (2012), the analysis that follows synthesizes the four family types and uses them to characterize the way different patient-surrogate pairs discussed advance care planning. Each family type has been given a new name for the purpose of this analysis that is intended to capture both the family's communication style and its attitudes toward end-of-life care decision making. Although Wittenberg Lyles et al. (2012) created their own nomenclature based on FCPT that could have been applied here, the names did not quite fit. The reasons for this new nomenclature are two-fold. First, while Wittenberg Lyles et al. (2012) sought to characterize only the way a caregiver provided care to a hospice patient, this analysis seeks to characterize attitudes and decision-making styles within a dyad of patient and surrogate. A second key difference in this study is that both patient and surrogate interacted in a joint interview. In Wittenberg-Lyles et al. (2012), interviews with patients and caregivers were conducted separately. The names and descriptions below try to capture the way the pair interacted during the joint conversation.

Each description includes an explanation of the family communication pattern type and a description of how pairs are characterized as exhibiting this type. Key differences in family communication type occurred in four key areas: the way families framed the problem of advance

care planning, how they expressed their attitudes toward family conflict, how they expressed their attitudes toward decision-making, and how they behaved during the interview. See Table 16 for the characteristics of each family type.

Independent deliberators. Members of this group have high conversation orientation and low conformity orientation and fit into the "pluralistic" category in FCPT. These are family members who engage in deliberative conversation (deliberators), talking out differences (independent). They are families in which members value conversation, and they also value their individual autonomy (Koerner et al., 2006). In other words, these families do not need to control other members by making decisions for them, but all opinions are valued and freely shared. And while members are encouraged to participate in decision-making (Sillars et al., 2014), there is not "overt pressure to conform or obey," and any conflicts are addressed openly (Koerner et al., 2006). Children who are members of this type of family have been found to have lower levels of verbal aggressiveness, which includes behavior such as teasing and name calling (Schrodt & Carr, 2012). In the hospice context, members of this group can talk openly about death, caregiver burden, and other complex issues (Wittenberg-Lyles et al., 2012).

Independent deliberators framed the problem of advance care planning in social terms, discussing how people talk out decisions. One patient-surrogate pair talked at length about how the surrogate would need "support" from his siblings to make end-of-life care decisions. When talking independently, the surrogate identified a need to "reach out" to any family member who would listen. It was important to independents who were surrogates to reach out to other family members to determine the best course of care for the patient, but they also wanted to exercise their own judgment to make the ultimate decision.

Table 16

FCPT-Based Advance Care Planning Communication Environments

	ACP Family Communication Environment			
Characteristic	Independent Deliberators	Removed Reserved	Discreet Defenders	Forceful Faction
FCPT Type	Pluralistic	Laissez-faire	Protective	Consensual
ACP Problem Framing	A talking, or social problem	Not a problem because the decision will be avoided	A problem of making patient's wants clear	A problem for others, but not for us because we know "the steps"
Attitudes Toward ACP	Decisions are difficult, but can be talked out.	Decisions are "too sad" to talk about.	Decisions should be made by family authority.	Decisions are not hard because "we're in sync" and information will be available.
Conflict Style	It is anticipated, but will be resolved.	It is not anticipated because no discussion will take place.	It is not anticipated because members who cannot follow the hierarchy should be excluded.	Members will resolve conflicts by explaining their reasons.
Observed Behavior	Back-and-forth, easy rapport between patient and surrogate	Tension between patient and surrogate, but no desire to discuss	Brief conversations and individual answers to questions	Some exchange of ideas, but one member is a strong conversation leader

The motto of one pair was that "it takes a village" to make good decisions, but they also believed it takes an individual surrogate to ultimately make a hard choice. What the surrogate and patient meant by that was that it would be helpful to get input from many sources, but the focus of that help should be weighing options so that the surrogate could make a good decision.

Independent deliberators anticipated that there would be conflict among family members, but that they would "talk out" or "fight out" disagreements "as best [they could]." Although one pair described family members as "coming out of the woodwork" and wanting too much say in the care of the patient, they were not afraid to tell others to "back off." One pair was concerned that conversation might lead to others trying to "win over" or influence the patient to their ideas. But overall, independents anticipated some disagreement during decision-making and that disagreement could be resolved.

During the interviews, independent deliberators wanted to talk deeply about the idea of advance care planning and preparing their families to make difficult decisions. They seemed to anticipate that their family members would be fraught with grief and would each deal with that grief differently. One pair questioned whether early advance care planning might even be meaningful because of the range of possible ways events could play out, but the surrogate in that pair affirmed that even if it was futile to "plan" anything, that conversation "couldn't hurt. It never hurts to discuss things." Another pair, a husband and wife with young adult grandchildren, wanted to talk with both their children and grandchildren about their decisions because "it's never too early" and they wanted to ensure that everyone was "prepared for the worst." The surrogate of the pair explained that they worried that one of their children would "get quiet" and the other would "get loud" in response to the stress of the feeding tube hypothetical.

The independent deliberators interviewed during this study had a genuine rapport with one another. Even though they were as avoidant as others were with the subject of death, patient-surrogate pairs talked about one another's feelings during the joint interview. As one surrogate put it, "It makes him really nervous to talk about [death]. His uncle died recently, and they were really close." The patient nodded in agreement. Patient and surrogates also took turns telling stories, offering information, and talking about ideas with the interviewer. The interviewer prompted some discussion topics, and in some cases topics seemed less comfortable (one surrogate began to describe being estranged from his father and said he did not want to "go there" during the interview), but on the whole, these pairs were engaged in the conversation.

Removed Reserved. Members of the removed reserved category have low conversation orientation and low conformity orientation and fit into the laissez-faire category of family communication environments (Koerner & Fitzpatrick, 2002b). These pairs got their name because they were easily diverted from the subject of decision-making and end-of-life care and did not share emotions, hence "reserved." They also told fewer stories about family experiences and appeared to know less about one another's inner lives, hence "removed." Laissez-faire family members have "few and often lifeless interactions" with family (Koerner et al., 2006). The topics involved in their conversations are limited. Family members are not interested in how others make decisions, and they are "emotionally divorced" (Koerner et al., 2006). Conflicts are uncommon in these families because they do not value talking out disagreements. Family members do not discuss their decisions and believe they will have to make decisions on their own; because they do not receive guidance on decision-making, they have doubts about their ability to make decisions (Koerner et al., 2006). In the hospice context, caregivers from these

families were said to hope for miracles and to concern themselves mainly with the details of daily care such as medication schedules (Wittenberg-Lyles et al., 2012).

Pairs in removed reserved environments framed the problem of advance care planning as not a problem at all, but for different reasons. In one pair, there would only be one choice: the patient would outlive the surrogate because, the surrogate said, "she makes me these long lists of chores. I too old for it. I'll get there first." Another member of a pair echoed the sentiment expressed in the description of caregivers in the laissez-faire style category created by Wittenberg-Lyles et al. (2012). They described caregivers in this category as hoping for miracles. The surrogate opened the joint part of the interview with a long story about a man who woke up from a 20-year coma. She was responding to the feeding tube hypothetical, saying she would never give up and that she would always hope for "some miracle" to "fall out of the sky. Because you never know. Those things happen all the time." For the removed reserved, some force would stop the need to make advance care planning decisions, whether it was the death of the surrogate or seeking out a miracle.

It was difficult to get members of these pairs to talk about decision-making. One pair spent the majority of the joint interview trying to remember the details of family member's death, trying to recall whether they were both present at the precise moment the family member died. Each could describe the moment, but the patient could not remember the surrogate being present. The surrogate seemed upset to hear this, asking the patient how she could forget sharing such an important moment. They began to disagree about what happened, but decided to "leave it. It doesn't matter." It was clear, though, that both were upset by the end of the exchange. The interviewer tried to steer the conversation back to talk about making decisions, and the patient said she would clearly need to do it herself since the pair could not "see eye to eye" about

anything. Other surrogates and patients in this group described decision-making in this context as "sad." One surrogate said that it was "too much" to think about because the patient is "her heart."

Members of these family communication environments did not anticipate conflict, but instead, as one surrogate put it, they would be "going it alone." There was no need to consult other family members to help in the decision-making because it would not be "worth it to bother them." Also notable regarding their discussion of potential conflict is what these people left out. One surrogate described "telling" her daughter when she made a decision for the patient, who had a serious health problem, in the past. The brevity of the statement tells the story—there would be no conflict about these decisions because there was no deliberation. When asked by the interviewer whether the surrogate would ever want her daughter's help in making the decision, the surrogate said, "she couldn't handle the responsibility. She's too young and busy." The daughter was in her late 20s.

A final note about the removed reserved is their behavior during the conversation. One pair in this group eagerly started the joint conversation saying they thought they had discussed advance care planning before. They discussed it when the patient's mother was "deadly sick, but survived." But when the patient suggested that the he wanted less aggressive care than the surrogate thought, it became clear that they had not talked about it, or at least had not come to an understanding about the patient's wishes. The patient said, "We're just going to have to talk about that." To verify, the individual portions of the interviews were reviewed. During the individual portion of the interview, the surrogate thought that the patient would want all measures taken to save his live, and in the patient's part, he discussed wanting palliative care in the event of a terminal illness. Another prominent feature of these interactions was the way the patient and surrogate interacted with the interviewer more often than with one another. In one

exchange that exemplifies this problem, the surrogate spent time telling a story about a relative who was forced to quit her job and become a full-time caretaker for a dying parent. This surrogate focused her story on how "awful" it must be to sit with that family member all day and be bored. The patient did not respond to the story or the surrogate's point, but turned to the interviewer and said, "next question," as if to say "let's move this along."

Discreet Defenders. Members of the discreet defenders have family environments that are low in conversation orientation and high in conformity orientation and fall into the protective category of family communication environments (Koerner & Fitzpatrick, 2002a, 2002b). Obedience is emphasized in these families. There is "little concern for conceptual matters or for open communication within the family" (Koerner & Fitzpatrick, 2002a, 2002b). These families believe that parents should be able to make decisions without having to explain their motives, and members are expected to avoid conflict. These families don't engage in conflict resolution because they do not value conversation and might not have the skills to do so (Koerner & Fitzpatrick, 2002a, 2002b). Children in these families "distrust their own decision-making ability" because they do not have family models for communicating decisions (Koerner & Fitzpatrick, 2002a, 2002b). In the hospice context, family members may think that they are protecting others by not talking about illness or death (Wittenberg-Lyles et al., 2012). Not talking about illness can also be seen as a way of maintaining family habits and not violating a common code of silence (Wittenberg-Lyles et al., 2012). These families may "appear to agree, but they have not, in fact, demonstrated their agreement in conversation" (Koerner & Fitzpatrick, 2002a, 2002b).

Members of these pairs framed advance care planning as focused on the patient's immediate needs and ensuring the patient can speak for themselves for as long as possible. One

pair of spouses told a story of a recent hospitalization the patient had for a serious, but temporary health condition. When telling the story, both patient and surrogate seemed bemused by the fact that the patient was able to give his assent to the physician for treatment despite the fact that he was so ill. He did so while his wife was out of the room, and even admitted to "not understanding [everything]" the doctor said. But the story itself is not what placed this pair in the Discreet Defenders category. It was the way the pair appeared to admire this behavior, as they were relieved that the patient maintained his authority, and there would be no disruption in the family's structure. A daughter surrogate from another pair said she could not imagine ever "having to" make a decision for the patient because the role reversal would be "too weird. He's the worst sick person. He won't listen to me now. I don't think he ever will." Later in the conversation, however, she promised she would put Chapstick on his lips when he was sick in bed, so long as he would let her.

When talking about decision-making, these pairs deferred to family hierarchy and refrained from sharing and described feeling confident that the family could "handle it." The same pair in which the surrogate characterized her authority as "weird" decided it might be more appropriate for the patient's brother to actually make the decision, and the surrogate would be the "megaphone" for it. The brother, the patient said, would "know what to do. End of story." The interviewer asked what might happen if there was a situation in which the surrogate were forced to make the decision on her own, the pair did not respond with an answer, but started a story about another family member's illness experience. This particular pair was perhaps either unable to imagine it, or, true to this family communication environment's description, unwilling to consider a disruption to traditional family roles and practices. The husband-wife pair that earlier described the husband's making a serious decision for himself when in the hospital ended their

conversation saying they were confident that their family would "talk it all over." This pair illustrates a trait that other pairs in this category demonstrated—they claimed they would talk with one another about advance care planning, but in the same interview either told a contradictory story about something that happened or they were clearly unaware of differing ideas about advance care planning the other person had.

Each of the pairs in this group did not think that conflict would be a problem for their decision-making, but two pairs discussed the fact that some family members should not be contacted, as one patient put it, "until it's all over." The pairs who fit into this category seemed to have a warm relationship with one another, but as exemplified by this quote, gave indications of being fairly insular. One motive for leaving family members out of the decision-making process is to avoid conflict and discussion of end-of-life care decisions with others, a characteristic that is associated with the protective family environment described in FCPT—and environment in which harmony and loyalty are favored over discussion and deliberation. It is worth noting, though, that the "discreet" part of this group's name comes from these discussions of the family members who should be left out of the decision-making process. When asked why, they would exclude some family members, they would not say. One pair, when asked, said that it was "a long story." In the joint interview for the other pair, the patient introduced a new topic of conversation. The unwillingness to talk about other family members in a potentially negative way is consistent with this family communication environment's protectiveness. It was as if the pairs wanted to avoid revealing any unsavory information or disparage family members who were not present.

A remarkable characteristic of the pairs in this group was that the joint conversations tended to be shorter than the others. Although the focus of this study is not to quantify such

differences, the brevity of the interviews conducted for this study is attributable at least in part to the relative harmony these pairs projected in some parts of the discussion. That is, as members of one pair claimed, they had "already agreed" on anything that would need to be done for end-of-life care, as if to render the discussion moot. As one patient put it, "We talk about everything. It's just that sometimes you've already done it all." The statement was friendlier than the avoidant ones made by Removed Reserved. It simply implied that the pair had reached the end of advance care planning, and there was nothing further to discuss. And, in fact, that patient's statement ended the interview.

Forceful factions. Members of these families are high in conversation orientation and high in conformity orientation and fit into the consensual group. These families had a strong sense of family structure and common ideas ("forceful") and found it important to align themselves with a family leader ("faction"). Within these families, there is a "pressure to agree and preserve the existing hierarchy" (Koerner et al., 2006, p. 15). Parents believe they should have the final say, but they are willing to spend time articulating their reasons why. Members usually value family conversations. Conflict is disfavored, but because it threatens members of the family, they will try to resolve the problem (Koerner et al., 2006). In the hospice context, members of this group can talk openly about death (Wittenberg-Lyles et al., 2012). However, these groups tend to involve "managers" who seek to steer decision-making with their authority.

Members of forceful factions framed advance care planning as a concept they were happy to talk about as it relates to others, but not to themselves, and they were eager to share their knowledge on the subject. They framed advance care planning as more of a problem for others than themselves because they "know each other." One surrogate argued during the joint interview, "we're not like [distant relatives]. We talk about why we think that way and what we

want." These pairs seemed uniquely confident in their responses to both the individual responses to the hypothetical and in the joint interview. One patient in this group read the feeding tube prompt and, during one of the initial questions, began reciting all of his knowledge about feeding tubes, including different types and their uses. He stated that he knew so much because he "did his homework," a statement that did not quite register in context because it implied that the patient had anticipated the prompt (he had no prior information about it). This example is emblematic of the way these pairs discussed the problem, though. It was, as a surrogate stated in his individual interview, "a matter of getting the right information and following the steps."

As mentioned earlier, these pairs were comfortable talking about the idea of advance care planning as it applied to others but tended to defer to more general discussion when asked questions about their own choices. During his individual interview, when asked for his preference in response to the hypothetical, one patient stated that he could not possibly respond to the prompt with the lack of information in it. Another surrogate, during the individual portion of the interview, was not sure what he would do under the circumstances, but he was sure that "good facts" would "help [him] figure out what to do and what [the patient] wanted."

Conflict was somewhat anticipated, but not discussed in detail. As one surrogate explained, "we can work it out, [even if we have to] explain over each other." In context, this statement indicated that the surrogate thought that she could talk with her family members. Her use of the word "explain," though is what places her response firmly in this family group. She viewed the purpose of talking as that of explicating one another's motives. Moreover, these pairs expressed that the decisions would not necessarily be easy to make, but it would be easy to reach consensus because "we think alike" and "I know [his] reasons." Members of these pairs did not see family conflict as something that would be a problem. To summarize their approach

to decision-making, one patient described needing to "whip [his son] into shape" so that he would know what the patient wanted.

Pairs had a warm rapport during the interviews, thought they sometimes seemed more comfortable talking about outside issues. During the joint interview, one of these pairs was interested in talking about a recent case in which life support was withdrawn, and another wanted to return to the details of the hypothetical in the individual portion of the interview to "get the facts" about whether it was a realistic scenario. Two groups in particular had a very dominant member throughout the conversation. This person set the topic of conversation, and their partners seemed to have an easy rapport with them, despite not contributing much of their own ideas to the conversation.

Conclusion

This study has analyzed the way patients and their surrogates talk about death, and it has described the way the family communication environment of patients and their surrogates was made manifest during these interviews.

Theoretical Implications

This study further extends the family environment types set forth in FCPT to describe patterns of family communication in advance care planning. Although studies involving FCPT have been applied to advance care planning situations, none has articulated family typologies related to decision-making and conflict management in these situations. Although decision-making is involved in many of the FCPT related studies, none attempt to articulate systematic differences in the way decisions might be made in these families. Because decision-making is ubiquitous, the results of this study could be used as a seed for an FCPT-derived decision-making typology for families that can be more widely applied.

Practical Implications

This work builds on the work of Wittenberg-Lyles et al (2012), presenting an argument that families communication environment types can be used as the basis for interventions and health policy in the area of end-of-life care. To address the way this study scaffolds on Wittenberg-Lyles et al (2012) directly, this work suggests that family communication patterns may affect family decision-making related to end-of-life care long before the patient is in hospice care. Because members of different family communication environments approach the problem of advance care planning differently, use different decision-making strategies, and approach conflict differently, these patterns likely affect the decisions leading up to hospice.

Limitations and Future Directions

This study has several limitations. First, this typology was developed using a very small sample in order to investigate these family environments with depth. Additional testing is needed with a larger population of dyads. Second, this sample contained a mixture of spouse and parent/child dyads. Many of the children operated in family communication environments with their own spouse and children and thus may operate in different family communication environments. Future work should test the categories developed on dyads in which the patient and surrogate have specific types of relationships to see if there are unique types that develop based on this criteria.

CHAPTER V

STUDY THREE

PATIENT ENGAGEMENT AND PHYSICIAN RESPONSIVENESS IN ADVANCE CARE PLANNING CONSULTATIONS: A MIXED-METHODS STUDY

Research Questions and Rationale

The clinical setting is a microsystem for advance care planning conversations that presents both barriers and facilitators of communication (Sudore & Fried, 2010). Study Three focuses on features of the clinical encounter as a microsystem that both inhibit and encourage patient engagement in advance care planning decision making. Many ecological factors, such as the participants' cultural beliefs, their use of technology, and even the built environment, have been given a great deal of attention because they affect the patient-physician interaction (Kreuter & McClure, 2004; Mallak et al., 2003; Street, 2003b). The relative success of these conversations depends not only on personal characteristics of the physician and patient, but their attitudes and communication behaviors (Street, 2003a). The overarching goal of Study Three is to describe what patients and physicians talk about in advance care planning consultations and how they talk about it, as well as to identify topics of conversation and patterns of interaction that promote or inhibit patient engagement and physician responsiveness in these interactions.

The nature of advance care planning and dealing with the idea of death is a challenge to patient-physician communication in these situations. In some patient-physician conversations involving advance care planning, patients and physicians struggle to even find language to talk about death. Rodriguez, Gambino, Butow, Hagerty and Arnold (2007) found that patients and

their physicians often avoided direct verbal references to death when it became part of the conversation. But frank conversation about death and dying, as well as related patient emotions can lead to more frank conversation about patient preferences for their care (Anderson, 2013). In fact, the physician's response to patient and family emotions about death is considered among the most missed opportunities in a clinical encounter (Curtis, 2008).

Some strategies for talking about advance care planning can encourage patient-physician conversation. Using metaphor and common language to understand health conditions helps patients and physicians build rapport and develop mutual understanding (Friberg, 2015). But it can have the effect of avoiding more nuanced or difficult conversation, such as conversation involving the level of uncertainty involved in advance care planning (Koedoot, 2004). Moreover, patients and physicians will sometimes adjust their conversation based on patient preferences for information-getting (White, 2007). When physicians sense a patient preference for less information, they may adjust the level of information they provide. Finally, clinical conversations can be adjusted based on patient and physician discomfort with uncertainty (Tulsky, 1998). Because advance care planning involves high levels of uncertainty, it created difficulties for patient and physician communication. This study thus first investigates what and how patients talk about

RQ1: How are issues related to advance care planning and end-of-life care decision making expressed by patients and addressed by physicians in clinical interactions?

This study also seeks to find larger conversational patterns that occur between patients and physicians when discussing the subject of advance care planning. This analysis involves finding both patterns of engagement within the individual advance care planning discourse of patients and physicians, as well as larger patterns of engagement in patient and physician

responses to one another across patient encounters. Because communication is a process of mutual influence, patients' and physicians' responses to one another shape an interaction (Street, 1991). Thus, they may prompt one another for specific responses (Gordon, Street, Kelly, Souchek, & Wray, 2005). For example, as Gordon et al. (2005) note, physicians may provide more information to patients who more often ask questions and express concerns.

Specific conversation patterns reflect the degree to which patients and clinicians are engaged in clinical discourse. Clinicians try to facilitate involvement through partnership-building and supportive talk (Street Jr et al., 2005; Street, Gordon, & Haidet, 2007). For example, a physician might engage in partnership building by encouraging the patient to express feelings or opinions. Or a physician might cultivate a supportive environment by empathizing with patients (Street, 1991). Both partnership-building and supportive talk have been found to positively influence patient participation in clinical encounters (Street Jr et al., 2005). Patients in turn engage in communication behaviors such as expressing concern; asserting their preferences, ideas, and needs; and asking questions (Street et al., 2007). This study seeks to uncover how these processes play out for patients and physicians engaged in consultations involving advance care planning. Thus this study additionally seeks to answer the following question:

RQ2: How do the ways patient and clinicians talk about advance care planning affect the patient engagement and physician responsiveness ratings assigned to the conversations by naïve observers?

Methods

Participants and Data Collection

This secondary data analysis uses a corpus of transcripts of 144 patient-physician interactions that were audio recorded as part of the PREPARE (Prepare for Your Care) protocol.

The PREPARE protocol is a randomized controlled trial conducted through the San Francisco Veteran's Administration Medical Center. The focus of the trial was activating patient participation in advance care planning by presenting it as a behavioral process that is iterative and requires conversation with both surrogate decision makers and physicians. Patients recruited to the study were all over 60 years old and were identified as having 2 or more chronic or severe medical conditions (Sudore et al., 2015). Additional inclusion criteria are detailed in the trial protocol explanation and elsewhere (Sudore et al., 2017; Sudore et al., 2015). Participant consent, as well as HIPAA waivers, were obtained according to local IRB rules as well as trial protocols.

PREPARE is a patient-based intervention designed to help patients identify their surrogate decision-makers, to designate surrogate decision-makers in documents adapted to be easier to read, and to complete advance directives specifying levels of medical care they wish to receive when their condition is terminal. Physicians recorded in these transcripts are primary care physicians and specialists who were not trained in the intervention, but some viewed the PREPARE content, which is available online at www.prepareforyourcare.org (Sudore et al., 2017; Sudore et al., 2015). Participants in the treatment arm viewed the online material, received copies of relevant documents, were offered a DVD of the material, and received a reminder call 1 to 3 days before their visit to bring completed advance care planning materials with them and to discuss their surrogate decision-maker as well as their advance care planning documents with their physician.

All 144 interactions included in the corpus involve patients assigned to the treatment arm of the study. Interactions were audio recorded, and written transcripts were created and verified by trained research assistants. Transcripts included only portions of the visit that contained

discussion of advance care planning, the PREPARE intervention, or other issues related to end-of-life care that could be attributed to the content of the intervention. The research assistants were trained to excerpt transcripts when the conversation turned away from PREPARE-related talk to other matters, including diagnostics and symptom management. Thus, some transcripts included multiple, separate episodes of conversation related to PREPARE that occurred at different points in the same visit. Visits with multiple episodes of relevant conversation are treated as a single "visit" in this analysis.

Of the visit transcripts included in the corpus, 60 contained no discussion of advance care planning, despite the intervention. This fact is noted here because it speaks to the difficulty of activating patients to discuss advance care planning, which has been document in previous research (Hines, 2001; Kass-Bartelmes & Hughes, 2004; Prendergast, 2001). Despite the online intervention, numerous take-home documents and materials, interactive portions of the intervention to complete, and reminder calls, 42% of patients did not mention advance care planning or the intervention during their visit. Eighty-four visit transcript excerpts have thus been analyzed here.

Measures

Independent coders evaluated the quality of patient-physician communication using scales adapted from the measure of patient-centered communication used by Street, Gordon, and Haidet (2007). This measure consists of two scales, one that measures patient engagement in the coded interaction, and another that measures physician responsiveness during the coded interaction. For this study, the patient and physician measures were used independently. While the original measures deal with general types of participation that indicate patient engagement

and physician responsiveness, measures were adapted for this study to apply explicitly to advance care planning.

The physician engagement measure includes 9 items on a 5-point Likert-style scale of agreement. Raters were asked to assess each physician's informativeness, sensitivity, and partnership building (encouraging the patient to express preferences, opinions, and concerns) with regard to advance care planning during the visit. Sample items include "The doctor was very informative about ACP," and "The doctor seemed to care about the patient's feelings about ACP."

The patient engagement measure includes 7 items on a 5-point Likert-style scale of agreement. Raters were asked to assess each patient's engagement in asking questions, expressing concerns, and asserting opinions and desires with regard to advance care planning during the visit. Sample items include "The patient asked the doctors to explain aspects of the ACP in greater detail," and "The patient freely expressed concerns and worries about ACP."

Most cases were evaluated by at least two coders. Some cases that included no discussion of advance care planning were only rated by a single coder, and these cases were not included in the reliability calculation. Interrater reliability for the patient engagement scale was good (α=.85). Interrater reliability for the physician responsiveness scale was also good (α=.89).

Analysis

In the initial phases of this study, elements of the constant comparison method were used, including an iterative coding scheme (Straus & Glaser, 1967). Content-related codes were developed by moving between the data in the transcripts and relevant literature involving advance care planning, including research involving designating surrogate decision makers, completing documents, and talking about death. Codes were developed based on themes found in

the literature that were reflected in the interactions, and these codes were further refined by revisiting the goal of identifying *what* patients and physicians talk about in advance care planning visits, as well as *how* they engage in clinical conversation about it. See Appendix H for this study's codebook.

Once an initial set of codes was developed, it became clear that two areas of interest that merited further study, each informed by ideas found in advance care planning, decision-making, and patient engagement literature. First, themes related specifically to decision-making about death and dying were examined. Secondary-cycle codes were developed based on the literature of decision-making and death and dying, as well as the themes found in the data to capture with more precision which issues related to death and dying patients were discussing, as well as how they were discussing them (Tracy, 2012). Second, it became clear that patients and physicians engaged in certain conversational moves that both promoted openness and engagement in decision-making during interaction and, in some cases, curtailed it. Collections of patient and physician utterances were separated into mini-episodes within clinical interactions, and axial codes were created to capture interaction patterns between patients and physician based on specific topics related to advance care planning (Charmaz, 2014; Strauss & Corbin, 1987).

After coding was completed in both of these areas of interest, the possibility that some subject matter discussed influenced patient participation and physician responsiveness became clear. The relationship between the qualitative analysis that had been completed and the patient-centered communication measures discussed above was investigated. The primary and secondary-cycle codes were thus revisited and streamlined for quantitative analysis. This streamlining included aggregating and disaggregating some of the subject matter codes that had been created. These streamlined codes were then statistically analyzed for their relationship to

the calculated patient engagement and physician responsiveness measures in order to uncover meaningful connections between the content of the conversations and both patient engagement and physician responsiveness.

Results

Thematic Analysis: Main Focus of Decision-Making in Episode

During the initial coding development, it became clear that the advance care planning conversation episodes fell into two distinct groups in terms of decision-making. A large number of the episodes focused exclusively on making decisions with regard to legal documents (n=33, 39%). These conversations primarily involved interactions in which patients and physicians discussed medical powers of attorney, advance directives, and the medical records in which these legal documents are preserved. Patients participated in these interactions by providing names and phone numbers of decision-makers, producing completed documents, and indicating when they wanted more time to think about their choices. Physicians responded by adding names and phone numbers to the medical record, inspecting completed documents, and encouraging patients to complete unfinished documents.

The remainder of the episodes in some cases included discussion of documents (n=17, 12%), but in all cases included conversation about end-of-life care decision-making that moved beyond documents. These episodes generally included a wider and richer array of themes. The richness of these conversations reflect current thinking in advance care planning research that suggests that legal documents are not effective communication prompts for discussing the wide array of decisions advance care planning encompasses (L. L. Emanuel, Danis, Pearlman, & Singer, 1995; Sudore & Fried, 2010). While legal documents require simple, immediate choices, advance care planning involves assessing longer-term goals, imagining a number of possible

outcomes, and anticipating the behavior of surrogate decision-makers (Fried, Bullock, Iannone, & O'Leary, 2009; Prendergast, 2001).

Despite more variation in conversation topics, subject matter beyond documents generally fell into two categories: surrogate decision-makers and patient treatment preferences for critical and end-of-life care. When discussing surrogate decision-makers, patients told stories about their own experiences serving as decision-makers for others, described their family members and friends, and provided rationales for choosing or not choosing individuals to make decisions for them. One patient described choosing a sister who is the "Tony Soprano of the family" because she would "handle everything." Another patient who chose his son over his wife as his surrogate decision-maker explained that his wife was "not happy" about his choice, but that he chose his son because of his wife's limited English proficiency and the fact that she "doesn't like to come to hospital."

When discussing treatment preferences for critical and end-of-life care, patients discussed a number of subjects. Some told stories about their healthcare experiences or the experiences of people close to them; some talked about concerns related to death and dying; and others discussed their rationale for wanting more or less care under critical circumstances. One patient described wanting to be kept alive at all costs so that his family could continue to receive his full monthly pension "for the family." Another patient described not wanting any "histrionics" in the event of brain death.

Thematic Analysis: Patients' Main Concerns About Decisions

Another subject that presented itself during second-round coding is patient and physician concerns related to decisions about death and dying. Discussion of advance care planning inevitably brings with it conversation about death and dying, a subject that often provokes fear

and anxiety (Brown et al., 2014). Both patients and physicians expressed concerns that are consistent with the body of literature describing this anxiety, but of particular interest here is how those concerns are expressed with regard to their own decision-making as well as the decision-making of others.

It was not surprising that homicide, suicide, and death with dignity often come up as concerns, as a way for patients to avert the complex decision-making involved in advance care planning. But it was somewhat surprising that these subjects were discussed with physicians in a clinical context. One patient feared that decision-makers might hasten his death, thinking a possible surrogate might reason "'Well, let him die because I'll get the money.'" Although this intervention took place in California, legal provisions for medically assisted were not yet fully in place when much of the data was collected (Roehr, 2018). Moreover, as of this writing, federal funding that the Veteran's Administration received cannot be used for physician assisted death (Harman & Magnus, 2017). Despite these realities, expressions of concerns about control over the circumstances of death were part of these conversations. One patient invoked the subject when discussing possible suffering from cancer treatment, saying "Assisted suicide: I am a big time believer in that…I think it's the noble thing to do…I have the moral right to go when I want to go." Another patient spoke not of assisted suicide, but of a more general "check-out plan," continuing, "When it gets to the point where all you guys say 'That's final,' you don't have to worry about me anymore, I'll deal with it." The language in the final statement suggests that the patient is willing to hasten his own death without working within the healthcare system, or with healthcare providers. Although suicide and assisted suicide are common topics related to end-of-life care, these topics appear to take on a different function when considering them in light of the literature of decision-making in advance care planning. In these conversations, they provide a

way for the patient to circumvent discussing decision-making further. Both literally and metaphorically, these ideas are an end point to the uncertainty involved in considering the myriad contingencies involved in a longer dying experience.

Similarly, concern about burdening family with not only care, but making healthcare decisions were included in these discussions. The literature of advance care planning has established that a primary patient concern with regard to end of life care is to not, as one patient put it, "be an inconvenience" to others. The "inconvenience" can include financial concerns regarding the cost of care and lost income, emotional burden, and strain on relationships (E. J. Emanuel, Fairclough, Slutsman, & Emanuel, 2000; Sharpe, Butow, Smith, McConnell, & Clarke, 2005). But another dimension of this burden that was made evident in these clinical episodes is the burden caused by uncertainty involved in making healthcare decisions as surrogate decision makers. A particularly clear illustration of this idea occurred when a patient described the experience of witnessing friends and family members "prolong their dying state," causing family to have to not only witness a long dying process, but to deal with the decisions involved in making care choices under these circumstances. The patient expressed that he did not want "the family to suffer" that way and wanted to make the decision to forego life-prolonging treatment so that family did not face a series of difficult decisions.

Another concern regarding advance care planning decision-making expressed by patients was the indignity of losing independence. Although the desire for independence and autonomy in patients, even those with serious illness, is well documented (Clayman et al., 2005), there are two reasons why it is worth noting in the context of advance care planning decision-making. First, there is a question of how realistic some patients' expectations of independence and autonomy is in terms of modern medical reality. As one patient put it when discussing the way their physician

and decision-maker should consider their quality of life, “If I can’t take care of myself,/ it's time to go.” While the patient did not list specifics in this episode, others mentioned the loss of the ability to wash themselves, to use the bathroom by themselves, and to make daily decisions. Many of these perceived indignities are ones that seriously ill patients must manage while still maintaining elements of their desired quality of life (Payne, Langley-Evans, & Hillier, 1996; Virdun, Luckett, Lorenz, Davidson, & Phillips, 2016). So there remains a question of how realistic these patient expectations are under the circumstances they will likely face as they get closer to the end of life. Second, and more explicitly related to decision-making are patient concerns about their surrogates or physicians making decisions on their behalf that compromise their dignity. A patient raised that possibility that another person might choose an experimental or painful life-prolonging treatment for her, she was concerned that “I’m going to be laying in bed the rest of my life drooling and defecating all over myself.” She wanted her physician and decision-maker to take on the decision-making mindset “when in doubt, we pull the plug.”

A final concern related to advance care planning decision-making expressed by patients was financial. The cost of unwanted life-prolonging care has been discussed in end-of-life care literature for decades (E. J. Emanuel et al., 2000; L. L. Emanuel et al., 1995). It is worth noting here because it does come up for patients in decision-making during advance care planning consultations in several ways. A common concern with cost in general is summed up in a patient’s stating, “I don’t want my life or my death to cause anybody to go through any money.” Another patient responded to a physician’s question about the level of care the patient would want in case of an accident or long-term illness by stating, “turn it off,” suggesting ending care in that event because “It saves a lot of money.” Another patient used a family example to discuss cost. He talked about not wanting life-sustaining care because his mother-in-law was in a nursing

home with memory problems, and despite the fact that she did not know where she was, her care was "costing $4000 a month." This theme is important to note in part because of the long-running debate over the cost of healthcare in the United States. While physicians might consider it distasteful, and perhaps unethical to discuss the cost of life-sustaining care with patients, it is a concern they wish to have considered during decision-making.

Thematic Analysis: Narratives

During secondary-cycle coding, another prominent feature of "how" patients discussed advance care planning decision-making was by telling stories. Although this study does not present an in-depth narrative analysis of the stories told by patients, it is an important feature of patient engagement that presents unique challenges and opportunities in advance care planning consultations. Emerging work in narrative medicine underscores the importance of patient storytelling as a form of engagement in the patient-physician encounter (Charon, 2001; Harter, Japp, & Beck, 2006). In the advance care planning context, narratives play a special role in these decision-making conversations.

Because advance care planning involves multiple levels of patient decision-making, from naming a surrogate decision-maker to deciding how the surrogate should make decisions, the context could be characterized as involving what decision scientists Tuckett and Nikolic call "radical uncertainty" (2017). In conditions of radical uncertainty, the situation is so uncertain that it is "impossible to represent the future in terms of a knowable and exhaustive list of outcomes." Under these circumstances, they argue that some storytelling becomes "conviction narrative" that serves the purpose of sense-making in terms of understanding potential problems, simulating future outcomes, gaining social support, and articulating a preferred course of action.

The stories told by patients in advance care planning consultations appear to serve these purposes in several specific ways: by justifying engaging in advance care planning, by forming a basis for their end-of-life treatment decisions and choice of surrogate decision-makers, and by articulating the certainty of death and fears about death and dying. Patients, and in some cases, physicians often began the conversation about advance care planning by discussing the importance of deciding on a surrogate decision maker and making their preferences for end-of-life care known. For these patients and physicians, the conversation was framed by a prevailing idea that even though end-of-life care is in essence an unpleasant topic of conversation, it is necessary, useful, and helpful. One patient told the story of taking care of his 93 year-old mother. He explained that it was difficult to "clear up a lot of decisions that she has made and for me to go through with her wishes." He then explained that his mother's desire to be cremated had become a problem that created tension with his siblings who were "not pleased" with this decision. He went on emphasize later that this was one decision among many related to her end-of-life care and death that made him glad that he was participating in his own advance care planning.

Other patients used storytelling as a means of explaining or justifying their choices. A patient who was explaining why he had chosen his son over his daughter as his surrogate decision-maker explained that his daughter was ill and was difficult to contact:

> Oh no, she'd never call me. She used to call me like, oh, she's all I had, I think she has Alzheimer's big time. She even forgets who she is. I've called her on it before she says "Oh, no, I don't have it." She must have that and that could do it. She wouldn't remember. If her husband said "Don't call," she said "Whatever." She doesn't remember saying that and that can happen with Alzheimer's. And like I said, my son and my

> daughter-in-law said "Yeah, you got to be careful of her, she doesn't like Mexicans and she's got a gun." So if I come over there, and she don't know who it is, she'll kill me. So I don't know how I'm going to correct that.

This particular story is chock full of details that describe a relationship that the patient wants to "correct," meaning here that he wants to restore communication with her despite her illness. Its level of detail (the above excerpt does not include the entire story) is illustrative. Although it could be dismissed as the patient providing "too much information," it provides a useful and concrete explanation for why the patient does not want his daughter involved in decision-making related to his care.

Other patients used stories to explain why they would forego life-saving care in favor of palliative measures should they have a terminal condition. A patient described the difficulty of experiencing his father's treatment after a stroke. His father's condition was such that "even the neurologist who was there said there is no hope for him." But because his father did not have an advance directive, the neurologist told the family that he must "do everything to try to help" the patient's father. The patient used this story to explain that he would choose only palliative care under those and other circumstances. Again, these details illustrate the patient's rationale for his choices.

Finally, patients used stories to talk about physical decline and death. One patient, a veteran with a great deal of physical training, explained the difficulty of coming to terms with death. He said, "Most of my friends have died from heart attacks and cancer, not so surprised that some of these guys got cancer or had a heart attack and stuff." However, he was surprised when he discovered that he had a congenital condition that would only get worse over time. He

described being in denial at first, “and I was like I don’t think so; but sure you can have a congenital defect.” He ultimately described the condition getting considerably worse over the years and combining with others. This story could be read as a means of dealing with the certainty of death, but uncertainty as to how precisely it will happen. Although the patient was not surprised about others, his story told of a condition that he couldn’t feel at one time, but would ultimately contribute to the decline of his health.

Thematic Analysis: Talk About Death

Decision-making in advance care planning inevitably includes conversation about death and dying. Past work has explored the difficulty of patient and physician talk about death and dying (Fine, Reid, Shengelia, & Adelman, 2010; Rodriguez et al., 2007). These discussions can trigger emotional responses and discomfort for both patients and physicians (Parry, Land, & Seymour, 2014). During secondary-cycle coding, language related to death in the patient-physician conversations began to stick out in several patterns of interest. A discussion of the language used to describe death is included in this analysis because of its relationship to patient engagement and decision-making: patients and physicians might mask their discomfort with the idea of death and their fears of death by using indirect language and references to talk about it.

Patients and physicians sometimes use indirect language to talk about death (Rodriguez et al., 2007), a behavior that may indicate their discomfort in talking about it. Both patients and physicians referred to death often using idioms. “Gone,” “sleep,” and “put down” were among those used in these consultations. One patient made reference to friends “dropping like flies.” Idioms that are perhaps peculiar to veterans are “put the flag down” and “give up the fight.” They also used phrases such as “pull the plug” and “turn it off” to describe withholding life-

sustaining care in general. These particular phrases, when used, offered a sort of punctuation mark to discussion of treatment choices, as if to say "end of life and end of discussion."

More striking than idioms used to talk about death are the language and references used to talk about unwanted life support and nutrition. This appears to reflect the idea than the biopolitical specter of cases such those of Terry Schiavo and Karen Ann Quinlan is still very much in the public consciousness. Several patients described the idea of an individual being "plugged in" to a machine and being kept alive "like a vegetable." In fact, the word vegetable was referenced 8 times in the corpus of conversations. References to machines, such as "plugged in," "pulling the plug," and being hooked up to a meter, appeared even more frequently. Patients also referenced these circumstances in popular culture and news. One patient mentioned the film "Johnny Got His Gun," a film about a soldier who is rendered trapped in his body, but fully conscious, by a devastating injury. Over the course of the film, the central character wishes that his caregivers would end his life. Another patient mentioned a then-current news story in which a young girl was on life support after a surgical complication. These mentions all appeared to reflect patient fears of "ending up that way."

Axial Coding: Physician and Patient Conversational Moves

Because this study is focused on patient engagement in advance care planning consultations, the next important step after examining the content of the conversations is to examine how interactions dealing with this subject matter play out. That is, how does the mutual back-and-forth between patients and physicians work, given the content of the conversation? This secondary coding draws on the literature that undergirds patient engagement, Speech Act Theory, which holds that the use of language within interactions accomplishes social acts (Austin, 1975; Searle, 1969). Interactants, in this case patients and physicians, use language not

only to describe their reality, but to build rapport, question, inform, express concerns, and advance opinions. Speech Act Theory is the basis for complete, comprehensive coding schemes, such as the Roter Interaction Analysis System, Street's measures of patient and physician participation, and the Generalized Medical Interaction Analysis System (Roter & Larson, 2002; Street Jr & Millay, 2001).

The analysis presented here is not an attempt to quantitatively and comprehensively describe the social actions undertaken in these interactions like the codes mentioned above. Rather, it is an attempt to describe exemplars, in the form of mini-episodes, that took place during the interactions that represent common conversational moves and to describe the advance care planning content discussed during those interactions. These exemplars are intended to describe parts of the interactions in which the "social acts" described above appear to promote or inhibit patient participation and physician engagement in interactions regarding advance care planning decision-making. Creation and further honing of secondary-cycle codes revealed four types of what will be called "conversational moves," speech acts made be patients and physicians that occurred during discussion of the topics discussed above. These conversational moves included asking open-ended and closed questions, validating one another, and blocking or ignoring topics.

Throughout secondary coding, a conversational move that appeared to impact participation and responsiveness was asking different types of questions, both closed- and open-ended questions. The use of open-ended questions in patient-physician consultations has been associated with increased patient satisfaction (Robinson & Heritage, 2006). A likely explanation for this increase in satisfaction is that open-ended questions require the patient to simply say more, to express concerns, to offer opinions, and to frame the conversation in their own terms.

Open-ended questions also leave physicians to listen more to keep the interaction going. The first exemplars show the difference between interactions in which physicians asked open- and closed-ended questions.

In this exemplar, a physician uses an open-ended question to solicit more explanation from a patient and to open up the conversation for storytelling. The physician and patient engaged in discussion of advanced care planning, and the physician used an open-ended question to probe a patient's feelings about death. The patient in this case refers to his combat experience:

> **Patient:** There were some really, really good experiences for me about my reality, my life, confronting life and death again, only this this time it wasn't behind a weapon or having a weapon pointed at me. This was like okay, it is completely different and it's like okay how do I deal with this.
>
> **Physician:** How was it different? What was different?
>
> **Patient:** Well the difference is you're trained to go out in combat and you know that they are trained to do combat, so it is going to be the guy that's got the best combat training who is going to win. Here I don't know.
>
> **Physician:** That's a great point.

The "how" and "what" questions asked here invite the patient to explore his feelings about death. While this point may seem obvious, the result of asking this open-ended question is that the patient explores the uncertainty associated with declining health. The physician has not only made a conversational move that encourages more patient participation, it also invites potentially useful information about the patient—he is grappling with uncertainty related to his declining health and ultimate death.

In this second exemplar, the patient opens up the discussion of patient treatment preferences with an open-ended question and follows up with closed question. The initial question invites a narrative response from the patient:

Physician: What about – what should I know medically; you've been intubated four times now?

Patient: [Lists all times and locations of intubations] The first time I became ill breathing. I remember the [supervisor] and I said I called 911 and she said what; you called 911? Who's going to replace you now? I said I don't know, I don't care, I called 911.

Physician: Should we do that again?

Patient: Yeah the reasoning was what about if we come to the point we find a problem let's say bringing me around and I said I thought about that over the years and I said if it came to a simple pass I don't want any heroics; pull the tube.

Physician: Okay if you had severe trouble breathing, would you want to be intubated?

Patient: Yes, yeah-

Physician: Okay so short term.

This exemplar shows that open-ended questions can invite stories from patients. Although stories can be disregarded as unnecessary information, the stories that patients tell in these visits are meaningful and useful. In this case, the patient's past experience of being intubated has led the patient to understand that intubation might be necessary for her in the short term, but not long term.

For the sake of contrast, this last question-related excerpt is a good exemplar for document-driven conversations. It, like most of the document-driven conversations shows how interactions involving long strings of closed questions play out:

Physician: Yeah I also understand wanting to take care of your family and so it is always –

Patient: And so I listed actually my uncle as primary and then my wife as secondary.

Physician: Can you show me that just so I know who –

Patient: Sure.

Physician: Oh so [Name] and he lives in [State]?

Patient: Yeah.

Physician: And have you discussed this directly with him?

Patient: Yeah I have. He understands.

Physician: And your wife knows?

Patient: Yeah and he also is the executor of my estate.

Physician: Okay and she knows that as well?

Patient: More or less. He is the executor and has always been the executor of my estate for the last twenty years.

The series of closed questions here solicit information from the patient in the context of filling out the advance directive. The patient in this case is telling the physician that he wants someone other than his wife as his surrogate decision maker. The physician asks the patient whether the patient has had a conversation with his surrogate decision maker. Because of the yes/no framing

of the question, patient participation is limited. Moreover, the closed question represents a missed opportunity for the physician to explore how/what the patient told his wife to probe for potential conflicts in future care.

Another conversational move that patients and physicians both used in the interactions is validation. In this case, validation is defined as an expression of approval for a behavior, a feeling, or an idea. In this exemplar, the physician validates the patient's communication with her surrogate decision-maker but praising the patient's description of communication:

Physician: I usually recommend that people choose somebody who understands what your wishes would be in those situations/ and could make decisions that you think would reflect your own wishes.

Patient: Yeah we briefly talked about this some time ago and I told her that and also when I go out of town, I always call her. When I went to New York, I said "I'm going to New York" just in case anything comes up.

Physician: That's wonderful, yeah. Okay.

Patient: If I am going to Las Vegas, I say "I am going to Las Vegas" and if anything would happen-

Physician: That's good. And so now that we've identified somebody that can make decisions for you if you are too sick to make them for yourself, it is still good for us to know what your wishes are just generally if you were so sick.

This exemplar captures both the positive and negative potential for validation that was seen in the conversations. On the one hand, the validation appears to create a positive atmosphere and to encourage the patient to not only continue the behavior, but to continue talking about it in the

conversation. The problem with validation in can be best seen in its second use by the physician ("That's wonderful"). The second use illustrates the passive, almost dismissive use of validation, as if to say "That's good—let's move on to something more relevant." This second use ultimately moved the interaction into a series of closed-ended questions.

Another conversational move used in some episodes by both patients and physicians was blocking. Blocking is defined here as a statement or statements that have the effect of cutting off conversation about a topic. As mentioned in a previous section, statements such as "pull the plug" and "end it" had the effect of stifling conversation about advance care planning decision-making. In some cases, blocking was more subtle:

Patient: I wish I had the form to show you but it is irrelevant and your time is better spent elsewhere. I like what they are trying to do, they said they have two groups and they are probably going to have a group that says these are the people who are going to act and these are the people who aren't going to act, I'm not sure; it's none of my business and I will stay with them as long as they are not wasting my time…

Physician: Yeah

Patient: and that sort of thing. That is an emotional thing not a time scheduling thing.

Physician: Well, I will let you continue your participation with them and we will talk about Advanced Directive at some point.

In this interaction, the patient has broached the subject of advance care planning with the physician, but then backs away from conversation about care choices, calling the discussion an "emotional thing." Blocking changes the tenor of the interaction—it affirms that some subjects are effectively off limits. In this case, and in others observed, the subject matter is death and the

difficult decisions made during end-of-life care. But in the context of advance care planning, a subject with well documented resistance and avoidance, pushing these blocks may be an important strategy to encourage patient engagement and physician responsiveness.

Quantitative Analysis: Patient Engagement and Physician Responsiveness

A final inquiry is whether the thematic analysis conducted in the project can be connected to measures of patient engagement and physician responsiveness. This inquiry is guided by the question: is there subject matter in advance care planning consultations that has the effect of increasing or decreasing patient engagement and physician responsiveness? To answer this question, all of the qualitative codes created were revisited. Codes related to the focus of the conversation and concerns patients had about advance care planning were tested against patient engagement and physician responsiveness measures. The result of note involves the focus of the conversation.

As discussed earlier, advance care planning conversations fell into two initial thematic categories: those dealing with legal documents, and those dealing with discussion of surrogate decision-makers and end-of-life care preferences. When these codes were re-examined, it was revealed that the majority of the advance care planning episodes that did not deal exclusively with documents had at least some discussion of surrogate decision makers and that end-of-life care preferences were not discussed exclusively. Ultimately, the categories of conversation were defined specifically as follows: conversations that dealt exclusively with filling out documents, without discussion of surrogate decision-makers beyond filling out demographic information; and conversations involving discussion of surrogate decision makers. These conversations had to include more than mere demographic information; they had to involve a substantive discussion

of subjects such the surrogate's relationship to the patient, a story involving the surrogate, or a reason why the person was chosen as a surrogate.

A two-by-two table plotting discussion of documents against discussion of surrogates was created. Figure 4 shows the descriptive statistics for conversations focusing on documents and conversation focusing on surrogate decision makers for all 144 clinical encounters included in the corpus analyzed. Again, it is noteworthy that 42% of the conversations in the entire corpus made no mention of advance care planning at all. As the figure shows, 21 conversations involved some discussion of advance care planning, but no discussion of surrogates or documents. These tended to be brief, and sometimes nebulous conversations about patient goals.

		Discussion of Surrogate: Yes	Discussion of Surrogate: No
Discussion of Documents	Yes	17 (12%)	33 (31%)
	No	12 (8%)	81 (56%) **60 (42%)**

Figure 4. Cross Tabulation of Document Discussion versus Surrogate Discussion

Each conversation type was then tested using both the patient engagement variable and the physician responsiveness variable as outcomes. A comparison of means was conducted using a one-way ANOVA test, the results of which are reported in Table 17, accompanied by the descriptive statistics for each group's scores on the engagement measures.

Table 17

Patient Engagement and Physician Responsiveness Mean Scores

	Conversation about Documents Only n=33		Conversation about Documents and Surrogates n=17		Conversation about Surrogates Only n=12		Conversations about neither Surrogates nor Documents n=81		One-Way Anova
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	
Patient Engagement Score	14.84	5.26	17.87	5.54	18.17	5.63	8.07	3.79	$F(3,139)=40.63$, $p=.000$***
Physician Responsiveness Score	25.06	11.12	32.16	8.31	29.36	9.86	10.44	4.72	$F(3,139)=65.68$, $p=.000$***

Note: *$p < .05$, **$p < .01$, ***$p < .001$

The tables below show multiple comparisons for engagement scores for both the patient engagement measure and the physician responsiveness measure using a post-hoc Tukey test. The

results of note here are the statistically significant difference in patient engagement when discussing documents only versus surrogates only.

Discussion of surrogates and not documents in consultations led to a mean patient engagement score of nearly 5 points higher when compared to discussion of documents alone, as shown in Table 18.

Table 18

Patient Engagement and Document versus Surrogate Conversations

Conversation Type		Mean difference	Standard error	*p*
Documents only vs.	Documents and surrogate	-2.94	1.40	.159
	Surrogate only	-4.87*	1.68	.023
Documents and surrogate vs.	Documents only	2.94	1.40	.159
	Surrogate only	-1.925	1.86	.73
Surrogate Only vs.	Documents only	4.87*	1.68	.023
	Documents and surrogate	1.925	1.86	.73

Note: $*p < .05$, $**p < .01$, $***p < .001$

For physicians, discussion of documents alone in consultations led to a mean responsieness score of nearly 8 points higher when compared to discussion of surrogates alone. Additionally, discussion of documents alone in consultations led to a mean physician responsiveness score of nearly 7 points higher when compared to discussion of surrogates and documents, as shown in Table 19.

Table 19

Physician Responsiveness and Document versus Surrogate Conversations

Conversation Type		Mean difference	Standard error	*p*
Documents only	Documents and surrogate	-6.86*	2.49	.034
	Surrogate only	-7.54*	2.99	.041
Documents and surrogate	Documents only	6.86*	2.49	.034
	Surrogate only	-0.68	3.31	.997
Surrogate Only	Documents only	7.54*	2.99	.041
	Documents and surrogate	0.68	3.31	.997

Note: $*p < .05$, $**p < .01$, $***p < .001$

Discussion

The aim of this study was to examine the content of advance care planning conversations and to link those findings to patterns of communication and to patient engagement and physician responsiveness. This study makes several important points that have both theoretical and practical implications.

Theoretical Implications

This study takes a unique approach to studying advance care planning in the clinical context. The qualitative coding sought to capture the subject matter of advance care planning consultations and to link that subject matter to intermediate outcomes along the way to the ultimate outcome, which is a good death, one that is on the patient's own terms. While other studies have in turns solidified patient engagement theories and practices, and described advance care planning in a clinical setting, this study marries the two. The implications for patient

engagement research are two-fold. First, this study makes an important point about clinical consultations that is sometimes lost in patient engagement literature—even within specific types of clinical visits, the focus of the conversation and the subject matter discussed within episodes and mini-episodes can be influential on a patient's level of participation in the conversation and a physician's responsiveness.

Second, this study underscores the fact that clinical encounters involving advance care planning are unique in that their goal is exclusively communicative. That is, the purpose of these advance care planning episodes is exclusively to communicate the immediate decisions regarding the patient's advance care planning documents and to consider future decisions that might be made with regard to the patient's care. This is significant in the development of patient engagement theory that is unique to this area. The focus of advance care planning consultations has historically been exclusively the execution of legal documents, but more recent efforts have focused on treating advance care planning as a social and behavioral process (Sudore & Fried, 2010). This study puts an even finer point this idea, suggesting that legal documents can actually get in the way of patients becoming engaged in these conversations with their physicians.

Practical Implications

This study also has a number of practical implications, the first of which relates to the findings of the quantitative analysis within the study. The results of this portion of the analysis suggest a gap in the subject matter that patients and physicians are more actively involved in during these consultations. Mean patient engagement was higher when discussing surrogates, which comports with common sense: patients probably have more to say about the people in their lives than they have to say about advance care planning documents. Likewise, mean physician responsiveness was higher when discussing the documents related to advance care

planning, a subject they also likely have more to say about during these consultations. How to best incorporate both the documents aspect of advance care planning and the "people" part should be the subject of further study.

The findings of this study are also important to consider in light of the recent Medicaid shift to physician reimbursement for advance care planning (Medicaid, 2015; Tuller, 2016). Quality standards for these codes are still in development, and the proposed measures only involve the completion of advance care planning documents. This study suggests there is much more involved in a high-quality consultation that fully engages patients, such as discussion of surrogate decision makers and identification of patient goals for their care. This study could thus be used at the basis for codes that are grounded in communication theory.

Finally, this study's dive into conversational moves in advance care planning consultations offers some concrete strategies for physicians who try to cultivate patient engagement. Asking open-ended questions, taking care to use validation strategically, and developing conversational moves that help confront blocking are concrete techniques that can be added to physician training. Moreover, making physicians aware of their "comfort zone" in advance care planning documents might help physicians develop their own strategies for approaching advance care planning consultations to that they venture into subject matter that provides more opportunity for patient engagement.

Limitations and Future Directions

This project has several limitations. As a study that attempts to capture communication patterns in advance care planning with depth, the breadth of the study is limited. First, the size of the corpus of interactions is relatively small, limiting the applicability of the both the qualitative and quantitative analysis. It is also important to note that the clinical encounters all occurred

within the same hospital system in the same geographic area. Individual physician practices, institutional values, and regional differences all also limit the applicability of the results.

Second, the bulk of this analysis was completed by a single coder. Additional coders should be trained on the codebooks developed and provide feedback as well as results for interrater comparison. A second step to ensure the integrity of the qualitative work here is to use verification processes, checking the veracity and relevance of the codes developed by sharing codebook elements with participants, physicians, and advance care planning experts.

Future should focus on testing the results of this one within diverse populations of physicians and patients. This would both provide validation or challenge to the findings of this study and uncover nuances in advance care planning consultations in different populations.

Conclusion

The communication processes involved in advance care planning are complicated, involving multiple stakeholders and decision making that is radically uncertain. Although studies like this one, might not make advance care planning itself any easier, it hopes to help improve the patient and physician communication, and by extension, patient decision-making, and ultimately the patient death experience.

CHAPTER VI

CONCLUSION

An important function of putting these three studies together is to make connections among them in order to lay a foundation for further work in this area. By using the ecological model as framework for thinking about advance care planning, the importance of both the family and the clinical environment has been emphasized. Thinking about advance care planning in this way solidifies the current paradigm shift in this area: advance care planning takes in both environments, and thus, factors in both environments bear on whether patients and their surrogates can engage in successful advance care planning (Sudore & Fried, 2010; Sudore et al., 2008).

Moreover, these results can be read together to see both connections between these environments, as well as key differences in them. One similarity between the environments pointed out in Study Two and Study Three is the way people talk about death. In their roles as both patients and family members, individuals not only used similar language to describe death, but used similar tactics to avoid discussing their own death in concrete terms. For example, in both family and clinical contexts, individuals used talk of suicide and homicide to avoid thinking about the indignities of death. When patients and families talked in this way, the effect was to stifle and inhibit further conversation about death. Understanding that these ways of talking about death are part of the larger ecology can help shift thinking to larger influences at play. Perhaps larger cultural forces (in the larger systems of the ecological model), including cultural

institutions and media, play a role in this way of thinking. These forces can be examined as part of the outer rings of the ecology of advance care planning.

A second contribution of this work, taken as a whole, is to add some texture to the concept of openness and to raise key questions about it conceptually. All three studies involve some element of "openness" about death, whether that openness extends to *what* is discussed or *how* it is discussed. Each study contributes in its own way to understanding what open communication about death means. In Study One, openness was measured using conversational partners' perceptions of it the frequency and extent of talk, as well as the subject matter. Study One found a positive relationship between this measure and concordance, suggesting that patient perceptions of surrogate openness are related to concordance. Studies Two and Three plumbed the concept implicitly. Both focused in part on the *what* of these conversations, cataloguing the content of conversations between patients and their family members, as well as patients and their physicians. Both studies also delved into the "how," describing conversational moves that both inhibit and inspire depth of conversation about death. Because death is such a sensitive subject, and because this subject underpins advance care planning, more work should be done to make openness a more clearly defined concept, both in terms of perceptions and behaviors.

Finally, Studies One and Two explore an important link between family communication environments and preferences for surrogate decision-making. These findings, take together, suggest that characterizing family communication environments using Family Communications Patterns Theory might offer unique insights into the way different families think about surrogate decision-making. In the current healthcare and legal environments, one specific standard, substituted judgment, is preferred. Using this standard, the surrogate is supposed to stand in the shoes of the patient to make decisions based on what the patient would want. Many suggest that

standard is not preferred by some (Torke, Alexander, & Lantos, 2008; Vig et al., 2006). The family communication environment in which patients and surrogates live prior to these decisions being made may have an important influence on how, why, and whether family members adopt the substituted judgment standard. Moreover, it might explain why some families struggle with it, and perhaps prefer other ways of making these decisions. It also suggests a possible larger pattern—one in which family communication environments can be used as a reference for collective decision-making preferences for different kinds of decisions, from the important to the trivial.

REFERENCES

Altheide, D. L., & Schneider, C. J. (2012). *Qualitative media analysis* (Vol. 38). Los Angeles, CA: Sage.

American Bar Association. (2005). Consumer's tool kit for health care advance planning: Washington DC: ABA Commission on Law and Aging. Retrieved from www.aba.org.

Arora, N. K. (2003). Interacting with cancer patients: the significance of physicians' communication behavior. *Social Science & Medicine, 57*(5), 791-806.

Austin, J. L. (1975). *How to do things with words*. London, England: Oxford University Press.

Badr, H., Smith, C. B., Goldstein, N. E., Gomez, J. E., & Redd, W. H. (2015). Dyadic psychosocial intervention for advanced lung cancer patients and their family caregivers: results of a randomized pilot trial. *Cancer, 121*(1), 150-158.

Baider, L. (2008). Communicating about illness: a family narrative. *Supportive Care in Cancer, 16*(6), 607-611.

Bandura, A. (1997). Self-efficacy: The exercise of control. New York: Freeman.

Brashers, D. E., Goldsmith, D. J., & Hsieh, E. (2002). Information seeking and avoiding in health contexts. *Human Communication Research, 28*(2), 258-271.

Bravo, G., Sene, M., & Arcand, M. (2017). Surrogate inaccuracy in predicting older adults' desire for life-sustaining interventions in the event of decisional incapacity: is it due in part to erroneous quality-of-life assessments? *International Psychogeriatrics, 29*(7), 1061-1068.

Bronfenbrenner, U. (1977). Toward an experimental ecology of human development. *American psychologist, 32*(7), 513-534.

Bronfenbrenner, U. (2001). Human development, bioecological theory of. In N. J. Smelser & B. Baltes (Eds.), *International encyclopedia of the social and behavioral sciences*. (pp. 10-69). New York: Elsevier.

Brown, A. J., Shen, M. J., Ramondetta, L. M., Bodurka, D. C., Giuntoli, R. L., & Diaz-Montes, T. (2014). Does death anxiety affect end-of-life care discussions? *International Journal of Gynecological Cancer, 24*(8), 1521-1526.

Bruce, C. R., Bibler, T., Childress, A. M., Stephens, A. L., Pena, A. M., & Allen, N. G. (2016). Navigating ethical conflicts between advance directives and surrogate decision-makers' interpretations of patient wishes. *CHEST Journal, 149*(2), 562-567.

Buss, D. M. (1997). Human social motivation in evolutionary perspective: Grounding terror management theory. *Psychological Inquiry, 8*(1), 22-26.

Bute, J. J., Petronio, S., & Torke, A. M. (2015). Surrogate decision makers and proxy ownership: Challenges of privacy management in health care decision making. *Health Communication, 30*(8), 799-809.

Centers for Medicare and Medicaid (2015). Advance Care Planning (ACP) as an Optional Element of an Annual Wellness Visit (AWV). *MLN Matters*.

Channick, S. A. (1999). The myth of autonomy at the end-of-life: Questioning the paradigm of rights. *Villanova Law Review, 44*, 577.

Charmaz, K. (2014). *Constructing grounded theory*. Los Angeles, CA: Sage.

Charon, R. (2001). Narrative medicine: a model for empathy, reflection, profession, and trust. *JAMA, 286*(15), 1897-1902.

Claxton-Oldfield, S., Crain, M., & Claxton-Oldfield, J. (2007). Death anxiety and death competency: The impact of a palliative care volunteer training program. *American Journal of Hospice and Palliative Medicine, 23*(6), 464-468.

Clayman, M. L., Makoul, G., Harper, M. M., Koby, D. G., & Williams, A. R. (2012). Development of a shared decision making coding system for analysis of patient–healthcare provider encounters. *Patient Education and Counseling, 88*(3), 367-372.

Clayman, M. L., Roter, D., Wissow, L. S., & Bandeen-Roche, K. (2005). Autonomy-related behaviors of patient companions and their effect on decision-making activity in geriatric primary care visits. *Social Science and Medicine, 60*(7), 1583-1591.

Clayton, J. M., Butow, P. N., Tattersall, M. H. N., Devine, R. J., Simpson, J. M., Aggarwal, G., . . . Lacey, J. (2007). Randomized controlled trial of a prompt list to help advanced cancer patients and their caregivers to ask questions about prognosis and end-of-life care. *Journal of Clinical Oncology, 25*(6), 715-723.

Craig, R. T. (1999). Communication theory as a field. *Communication Theory, 9*(2), 119-161.

Creswell, J. W. (2013). *Research design: Qualitative, quantitative, and mixed methods approaches*. Thousand Oaks, CA: Sage publications.

Cullum-Swan, B., & Manning, P. (1994). Narrative, content, and semiotic analysis. In N. K. Denzin & Y.S. Lincoln (Eds.), (pp. 463-477). Thousand Oaks, CA: Sage.

de Bernardo, D. H., & Curtis, A. (2013). Using online and paper surveys: the effectiveness of mixed-mode methodology for populations over 50. *Research on Aging, 35*(2), 220-240.

Desharnais, S., Carter, R. E., Hennessy, W., Kurent, J. E., & Carter, C. (2007). Lack of concordance between physician and patient: reports on end-of-life care discussions. *Journal of Palliative Medicine, 10*(3), 728-740.

Dixon, J., Matosevic, T., & Knapp, M. (2015). The economic evidence for advance care planning: systematic review of evidence. *Palliative Medicine, 29*(10), 869-884.

Dumont, S., Turgeon, J., Allard, P., Gagnon, P., Charbonneau, C., & Vézina, L. (2006). Caring for a loved one with advanced cancer: determinants of psychological distress in family caregivers. *Journal of Palliative Medicine, 9*(4), 912-921.

Emanuel, E. J., Fairclough, D. L., Slutsman, J., & Emanuel, L. L. (2000). Understanding economic and other burdens of terminal illness: the experience of patients and their caregivers. *Annals of Internal Medicine, 132*(6), 451-459.

Emanuel, L. L., Danis, M., Pearlman, R. A., & Singer, P. A. (1995). Advance care planning as a process: structuring the discussions in practice. *Journal of the American Geriatrics Society, 43*(4), 440-446.

Emery, F. E., & Trist, E. L. (2012). *Towards a social ecology: Contextual appreciations of the future in the present*. New York: Springer Science & Business Media.

End of Life Care. (2012). *Dartmouth Atlas of Health Care.*

Engelberg, R. A., Patrick, D. L., & Curtis, J. R. (2005). Correspondence between patients' preferences and surrogates' understandings for dying and death. *Journal of Pain and Symptom Management, 30*(6), 498-509.

Epstein, R. M. (2013). The ambiguity of personhood. *American Journal of Bioethics, 13*(8), 42-44.

Epstein, R. M., & Street, R. L. (2011). Shared mind: communication, decision making, and autonomy in serious illness. *The Annals of Family Medicine, 9*(5), 454-461.

Fine, E., Reid, M. C., Shengelia, R., & Adelman, R. D. (2010). Directly observed patient–physician discussions in palliative and end-of-life care: A systematic review of the literature. *Journal of Palliative Medicine, 13*(5), 595-603.

Fisher, W. R. (1985). The narrative paradigm: An elaboration. *Communications Monographs, 52*(4), 347-367.

Freytag, J., & Rauscher, E. A. (2017). The Importance of Intergenerational Communication in Advance Care Planning: Generational Relationships among Perceptions and Beliefs. *Journal of Health Communication*, 1-9.

Fried, T. R., Bullock, K., Iannone, L., & O'Leary, J. R. (2009). Understanding advance care planning as a process of health behavior change. *Journal of the American Geriatrics Society, 57*(9), 1547-1555.

Fritch, J., Petronio, S., Helft, P. R., & Torke, A. (2013). Making decisions for hospitalized older adults: ethical factors considered by family surrogates. *The Journal of Clinical Ethics, 24*(2), 125.

Frosch, D. L., May, S. G., Rendle, K. A. S., Tietbohl, C., & Elwyn, G. (2012). Authoritarian physicians and patients' fear of being labeled 'difficult'among key obstacles to shared decision making. *Health Affairs, 31*(5), 1030-1038.

Goldsmith, D. J., & Domann-Scholz, K. (2013). The meanings of "open communication" among couples coping with a cardiac event. *Journal of Communication, 63*(2), 266-286.

Gordon, H. S., Street, R. L., Kelly, P. A., Souchek, J., & Wray, N. P. (2005). Physician–patient communication following invasive procedures: an analysis of post-angiogram consultations. *Social Science & Medicine, 61*(5), 1015-1025.

Hagerty, R. G., Butow, P. N., Ellis, P. M., Lobb, E. A., Pendlebury, S. C., Leighl, N., . . . Tattersall, M. H. N. (2005). Communicating with realism and hope: incurable cancer patients' views on the disclosure of prognosis. *Journal of Clinical Oncology, 23*(6), 1278-1288.

Hajizadeh, N., Uhler, L., Herman, S. W., & Lester, J. (2016). Is shared decision making for end-of-life decisions associated with better outcomes as compared to other forms of decision making? A systematic literature review. *MDM Policy & Practice, 1*(1).

Halpern, S. D. (2012). *Shaping end-of-life care: behavioral economics and advance directives.* Paper presented at the Seminars in respiratory and critical care medicine.

Hamon, J. D., & Schrodt, P. (2012). Do parenting styles moderate the association between family conformity orientation and young adults' mental well-being? *Journal of Family Communication, 12*(2), 151-166.

Harman, S. M., & Magnus, D. (2017). Early experience with the California end of life option act: balancing institutional participation and physician conscientious objection. *JAMA internal medicine, 177*(7), 907-908.

Harter, L. M., Japp, P. M., & Beck, C. S. (2006). *Narratives, health, and healing: Communication theory, research, and practice*. New York: Routledge.

Hesse, C., Rauscher, E. A., Goodman, R. B., & Couvrette, M. A. (2017). Reconceptualizing the role of conformity behaviors in Family Communication Patterns Theory. *Journal of Family Communication, 17*(4), 319-337.

Hines, S. C. (2001). Coping with uncertainties in advance care planning. *Journal of Communication, 51*(3), 498-513.

Hoerger, M., Epstein, R. M., Winters, P. C., Fiscella, K., Duberstein, P. R., Gramling, R., . . . Tang, W. (2013). Values and options in cancer care (VOICE): study design and rationale for a patient-centered communication and decision-making intervention for physicians, patients with advanced cancer, and their caregivers. *BMC Cancer, 13*(1), 1.

Hsieh, H.-F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research, 15*(9), 1277-1288.

Karel, M. J., Moye, J., Bank, A., & Azar, A. R. (2007). Three methods of assessing values for advance care planning comparing persons with and without dementia. *Journal of Aging and Health, 19*(1), 123-151.

Kass-Bartelmes, B. L., & Hughes, R. (2004). Advance care planning: preferences for care at the end of life. *Journal of Pain and Palliative Care Pharmacotherapy, 18*(1), 87-109.

Kazak, A. E. (1989). Families of chronically ill children: a systems and social-ecological model of adaptation and challenge. *Journal of Consulting and Clinical Psychology, 57*(1), 25.

Keating, D. M. (2016). Conversation orientation and conformity orientation are inversely related: A meta-analysis. *Communication Research Reports, 33*(3), 195-206.

Kenny, D. A., Kashy, D. A., Cook, W. L., & Simpson, J. (2006). Dyadic data analysis (Methodology in the social sciences). New York, NY: Guilford.

Khandelwal, N., Kross, E. K., Engelberg, R. A., Coe, N. B., Long, A. C., & Curtis, J. R. (2015). Estimating the effect of palliative care interventions and advance care planning on ICU utilization: a systematic review. *Critical Care Medicine, 43*(5), 1102.

Koerner, A. F., & Fitzpatrick, M. A. (2002a). Toward a theory of family communication. *Communication Theory, 12*(1), 70-91.

Koerner, A. F., & Fitzpatrick, M. A. (2002b). Understanding family communication patterns and family functioning: The roles of conversation orientation and conformity orientation. *Annals of the International Communication Association, 26*(1), 36-65.

Koerner, A. F., Fitzpatrick, M. A., Braithwaite, D., & Baxter, L. (2006). Family communication patterns theory: A social cognitive approach. In D.O. Braithwaite, E. A. Suter, & K. Floyd. *Engaging theories in Family Communication: Multiple Perspectives,* (pp. 50-65). London, England: Routledge.

Koerner, A. F., & Schrodt, P. (2014). An introduction to the special issue on family communication patterns theory. *Journal of Family Communication, 14*(1), 1-15.

Kon, A. A. (2010). The shared decision-making continuum. *JAMA, 304*(8), 903-904.

Kramer, B. J., Kavanaugh, M., Trentham-Dietz, A., Walsh, M., & Yonker, J. A. (2009). Predictors of family conflict at the end of life: the experience of spouses and adult children of persons with lung cancer. *The Gerontologist,* 100-121.

Kreuter, M. W., & McClure, S. M. (2004). The role of culture in health communication. *Annual Review of Public Health, 25,* 439-455.

Lai, P. S. M., Mudri, S. M., Chinna, K., & Othman, S. (2016). The development and validation of the advance care planning questionnaire in Malaysia. *BMC Medical Ethics, 17*(1), 61.

Larson, E. B., & Yao, X. (2005). Clinical empathy as emotional labor in the patient-physician relationship. *JAMA, 293*(9), 1100-1106.

Layde, P. M., Beam, C. A., Broste, S. K., Connors Jr, A. F., Desbiens, N., Lynn, J., . . . Vidaillet, H. (1995). Surrogates' predictions of seriously ill patients' resuscitation preferences. *Archives of Family Medicine, 4*(6), 518.

Ledbetter, A. M. (2009). Family communication patterns and relational maintenance behavior: Direct and mediated associations with friendship closeness. *Human Communication Research, 35*(1), 130-147.

Leventhal, H., Jessica, S. Y., Leventhal, E. A., & Bodnar-Deren, S. M. (2016). Cognitive Mechanisms and Common-Sense Management of Cancer Risk: Do Patients Make Decisions? In M.A. Difenbach, S. Miller-Halegoua, & D. J. Bowen (Eds.). *Handbook of Health Decision Science* (pp. 87-108). New York: Springer.

Loewenstein, G. (2005). Projection bias in medical decision making. *Medical Decision Making, 25*(1), 96-105.

Lum, H. D., Jones, J., Matlock, D. D., Glasgow, R. E., Lobo, I., Levy, C. R., . . . Kutner, J. S. (2016). Advance care planning meets group medical visits: the feasibility of promoting conversations. *The Annals of Family Medicine, 14*(2), 125-132.

Macnamara, J. R. (2005). Media content analysis: Its uses, benefits and best practice methodology. *Asia-Pacific Public Relations Journal, 6*(1), 1.

Mallak, L. A., Lyth, D. M., Olson, S. D., Ulshafer, S. M., Ulshafer, S. M., & Sardone, F. J. (2003). Culture, the built environment and healthcare organizational performance. *Managing Service Quality: An International Journal, 13*(1), 27-38.

Maly, R. C., Frank, J. C., Marshall, G. N., DiMatteo, M. R., & Reuben, D. B. (1998). Perceived efficacy in patient-physician interactions (PEPPI): Validation of an instrument in older persons. *Journal of the American Geriatrics Society, 46*(7), 889-894.

Marckmann, G. (2013). The economics of advance care planning: empirical data and ethical implications. *BMJ Supportive & Palliative Care, 3*(2), 241-241.

Marks, M. A. Z., & Arkes, H. R. (2008). Patient and surrogate disagreement in end-of-life decisions: can surrogates accurately predict patients' preferences? *Medical Decision Making, 28*(4), 524-531.

Mazer, J. P., & Thompson, B. (2011). The validity of the Student Academic Support Scale: Associations with social support and relational closeness. *Communication Reports, 24*(2), 74-85.

McHugh, M. L. (2012). Interrater reliability: the kappa statistic. *Biochemia Medica, 22*(3), 276-282.

McIntosh, J. M., Lyon, A. R., Carlson, G. A., Everette, C. D., & Loera, S. (2008). Measuring the mesosystem: A survey and critique of approaches to cross setting measurement for ecological research and models of collaborative care. *Families, Systems, & Health, 26*(1), 86.

Mebane, E. W., Oman, R. F., Kroonen, L. T., & Goldstein, M. K. (1999). The influence of physician race, age, and gender on physician attitudes toward advance care directives and preferences for end-of-life decision-making. *Journal of the American Geriatrics Society, 47*(5), 579-591.

Mesters, I., Van Den Borne, H., McCormick, L., Pruyn, J., De Boer, M., & Imbos, T. (1997). Openness to discuss cancer in the nuclear family: scale, development, and validation. *Psychosomatic Medicine, 59*(3), 269-279.

Metts, S., & Lamb, E. (2006). Methodological approaches to the study of family communication. In L.H. Turner & R. West (Eds.). *The Family Communication Sourcebook*, (pp. 83-105). Thousand Oaks, CA: Sage.

Moorman, S. M., & Carr, D. (2008). Spouses' effectiveness as end-of-life health care surrogates: accuracy, uncertainty, and errors of overtreatment or undertreatment. *The Gerontologist, 48*(6), 811-819.

Moorman, S. M., Hauser, R. M., & Carr, D. (2009). Do older adults know their spouses' end-of-life treatment preferences? *Research on Aging, 21*(2), 135-138.

Moran, M. B., Frank, L. B., Zhao, N., Gonzalez, C., Thainiyom, P., Murphy, S. T., & Ball-Rokeach, S. J. (2016). An argument for ecological research and intervention in health communication. *Journal of health communication, 21*(2), 135-138.

Müller, E., Hahlweg, P., & Scholl, I. (2016). What do stakeholders need to implement shared decision making in routine cancer care? A qualitative needs assessment. *Acta Oncologica*, 1-8.

Navarrete, C. D., & Fessler, D. M. (2005). Normative bias and adaptive challenges: A relational approach to coalitional psychology and a critique of terror management theory. *Evolutionary Psychology, 3*(1), 141-147.

Noller, P., & Fitzpatrick, M. A. (1993). *Communication in family relationships*: New York: Prentice-Hall.

Northouse, L. L., Mood, D. W., Montie, J. E., Sandler, H. M., Forman, J. D., Hussain, M., . . . Kershaw, T. (2007). Living with prostate cancer: patients' and spouses' psychosocial status and quality of life. *Journal of Clinical Oncology, 25*(27), 4171-4177.

Parker, S. M., Clayton, J. M., Hancock, K., Walder, S., Butow, P. N., Carrick, S., . . . Hagerty, R. (2007). A systematic review of prognostic/end-of-life communication with adults in the advanced stages of a life-limiting illness: patient/caregiver preferences for the content,

style, and timing of information. *Journal of pain and symptom management, 34*(1), 81-93.

Parry, R., Land, V., & Seymour, J. (2014). How to communicate with patients about future illness progression and end of life: a systematic review. *BMJ Supportive & Palliative Care, 4*(4), 331-341.

Payne, S., Langley-Evans, A., & Hillier, R. (1996). Perceptions of a'good'death: a comparative study of the views of hospice staff and patients. *Palliative Medicine, 10*(4), 307-312.

Pearlman, R. A., Cole, W. G., Patrick, D. L., Starks, H. E., & Cain, K. C. (1995). Advance care planning: Eliciting patient preferences for life-sustaining treatment. *Patient education and counseling, 26*(1), 353-361.

Pecchioni, L. L., & Nussbaum, J. F. (2000). The influence of autonomy and paternalism on communicative behaviors in mother-daughter relationships prior to dependency. *Health Communication, 12*(4), 317-338.

Porensky, E. K., & Carpenter, B. D. (2008). Knowledge and perceptions in advance care planning. *Journal of Aging and Health, 20*(1), 89-106.

Prendergast, T. J. (2001). Advance care planning: pitfalls, progress, promise. *Critical Care Medicine, 29*(2), 34-39.

Ritchie, L. D., & Fitzpatrick, M. A. (1990). Family communication patterns measuring intrapersonal perceptions of interpersonal relationships. *Communication Research, 17*(4), 523-544.

Robinson, J. D., & Heritage, J. (2006). Physicians' opening questions and patients' satisfaction. *Patient education and counseling, 60*(3), 279-285.

Rodenbach, R. A., Rodenbach, K. E., Tejani, M. A., & Epstein, R. M. (2016). Relationships between personal attitudes about death and communication with terminally ill patients: How oncology clinicians grapple with mortality. *Patient Education and Counseling, 99*(3), 356-363.

Rodriguez, K. L., Gambino, F. J., Butow, P., Hagerty, R., & Arnold, R. M. (2007). Pushing up daisies: implicit and explicit language in oncologist–patient communication about death. *Supportive Care in Cancer, 15*(2), 153-161.

Roehr, B. (2018). Assisted dying in US and Canada: controversy subsides after legalisation. *BMJ, 360*(4), 132-140.

Rogers, L. E. (2001). Relational communication in the context of family. *Journal of Family Communication, 1*(1), 25-35.

Roter, D., & Larson, S. (2002). The Roter interaction analysis system (RIAS): utility and flexibility for analysis of medical interactions. *Patient Education and Counseling, 46*(4), 243-251.

Schrodt, P., & Carr, K. (2012). Trait verbal aggressiveness as a function of Family Communication Patterns. *Communication Research Reports, 29*(1), 54-63.

Schrodt, P., Witt, P. L., & Messersmith, A. S. (2008). A meta-analytical review of family communication patterns and their associations with information processing, behavioral, and psychosocial outcomes. *Communication Monographs, 75*(3), 248-269.

Scott, A. M., & Caughlin, J. P. (2015). Communication nonaccommodation in family conversations about end-of-life health decisions. *Health Communication, 30*(2), 144-153.

Searle, J. R. (1969). *Speech acts: An essay in the philosophy of language* (Vol. 626). London: Cambridge University Press.

Shalowitz, D. I., Garrett-Mayer, E., & Wendler, D. (2006). The accuracy of surrogate decision makers: a systematic review. *Archives of Internal Medicine, 166*(5), 493-497.

Sharf, B. F. (2016). Communicating Health through Narratives. *Storied Health and Illness: Communicating Personal, Cultural, and Political Complexities*. Thousand Oaks, CA: Sage.

Sharf, B. F. &Vanderford, M. L. (2003). Illness narratives and the social construction of health. In T.L. Thompson, A. Dorsey, K. I. Miller, & R. Parrott. *Handbook of HealthCcommunication* (pp. 9-34) Thousand Oaks, CA: Sage.

Sharpe, L., Butow, P., Smith, C., McConnell, D., & Clarke, S. (2005). The relationship between available support, unmet needs and caregiver burden in patients with advanced cancer and their carers. *Psycho-Oncology, 14*(2), 102-114.

Shin, D. W., Cho, J., Roter, D. L., Kim, S. Y., Yang, H. K., Park, K., . . . Park, J. H. (2016). Attitudes Toward Family Involvement in Cancer Treatment Decision Making: The Perspectives of Patients, Family Caregivers, and Their Oncologists. *Psycho-Oncology*. *14*(2), 102-114.

Sillars, A., Holman, A. J., Richards, A., Jacobs, K. A., Koerner, A., & Reynolds-Dyk, A. (2014). Conversation and conformity orientations as predictors of observed conflict tactics in parent-adolescent discussions. *Journal of Family Communication, 14*(1), 16-31.

Silveira, M. J., DiPiero, A., Gerrity, M. S., & Feudtner, C. (2000). Patients' knowledge of options at the end of life: ignorance in the face of death. *JAMA, 284*(19), 2483-2488.

Singer, P. A., Martin, D. K., & Kelner, M. (1999). Quality end-of-life care: patients' perspectives. *JAMA, 281*(2), 163-168.

Straus, A. L., & Glaser, B. (1967). The discovery of grounded theory: Strategies for qualitative research. Chicago: Aldine Publications Company.

Strauss, A. C., & Corbin, J. (1987). J.(1990) Basics of qualitative research. Thousand Oaks, CA: Sage.

Street, R. L. (1991). Information-giving in medical consultations: the influence of patients' communicative styles and personal characteristics. *Social Science & Medicine, 32*(5), 541-548.

Street, R. L. (2003a). Communication in medical encounters: An ecological perspective. In T. Thompson, A. Dorsey, K. Miller, & R. Parrott (Eds.), *Handbook of health communication* (pp. 63-89). Mahwah, NJ: Lawrence Erlbaum Associates.

Street, R. L. (2003b). Mediated consumer–provider communication in cancer care: the empowering potential of new technologies. *Patient Education and Counseling, 50*(1), 99-104.

Street, R. L., Gordon, H., & Haidet, P. (2007). Physicians' communication and perceptions of patients: is it how they look, how they talk, or is it just the doctor? *Social Science & Medicine, 65*(3), 586-598.

Street, R. L., Gordon, H. S., Ward, M. M., Krupat, E., & Kravitz, R. L. (2005). Patient participation in medical consultations: why some patients are more involved than others. *Medical Care, 43*(10), 960-969.

Street, R. L., & Millay, B. (2001). Analyzing patient participation in medical encounters. *Health Communication, 13*(1), 61-73.

Sudore, R., Boscardin, J., Feuz, M. A., McMahan, R. D., Katen, M. T., & Barnes, D. E. (2017). Effect of the PREPARE website vs an easy-to-read advance directive on advance care

planning documentation and engagement among Veterans: a randomized clinical trial. *JAMA Internal Medicine, 177*(8), 1102-1109.

Sudore, R., & Fried, T. R. (2010). Redefining the "planning" in advance care planning: preparing for end-of-life decision making. *Annals of Internal Medicine, 153*(4), 256-261.

Sudore, R., Le, G. M., McMahan, R., Feuz, M., Katen, M., & Barnes, D. E. (2015). The advance care planning PREPARE study among older Veterans with serious and chronic illness: study protocol for a randomized controlled trial. *Trials, 16*(1), 570.

Sudore, R., Schickedanz, A. D., Landefeld, C. S., Williams, B. A., Lindquist, K., Pantilat, S. Z., & Schillinger, D. (2008). Engagement in multiple steps of the advance care planning process: a descriptive study of diverse older adults. *Journal of the American Geriatrics Society, 56*(6), 1006-1013.

Temel, J. S., Greer, J. A., Muzikansky, A., Gallagher, E. R., Admane, S., Jackson, V. A., . . . Pirl, W. F. (2010). Early palliative care for patients with metastatic non–small-cell lung cancer. *New England Journal of Medicine, 363*(8), 733-742.

Templer, D. I., Ruff, C. F., & Franks, C. M. (1971). Death anxiety: Age, sex, and parental resemblance in diverse populations. *Developmental Psychology, 4*(1), 108.

The Conversation Project. (2013). First National Survey on End-of-Life Conversations. Retrieved from http://theconversationproject.org/press-release-first-national-survey-on-end-of-life-conversations/

Torke, A. M., Alexander, G. C., & Lantos, J. (2008). Substituted judgment: the limitations of autonomy in surrogate decision making. *Journal of General Internal Medicine, 23*(9), 1514-1517.

Torke, A. M., Sachs, G. A., Helft, P. R., Montz, K., Hui, S. L., Slaven, J. E., & Callahan, C. M. (2014). Scope and outcomes of surrogate decision making among hospitalized older adults. *JAMA Internal Medicine, 174*(3), 370-377.

Tracy, S. J. (2012). *Qualitative research methods: Collecting evidence, crafting analysis, communicating impact*. New York: John Wiley & Sons.

Tuckett, D., & Nikolic, M. (2017). The role of conviction and narrative in decision-making under radical uncertainty. *Theory & Psychology, 27*(4), 501-523.

Tuller, D. (2016). Medicare Coverage For Advance Care Planning: Just The First Step. *Health affairs (Project Hope), 35*(3), 390.

Vangelisti, A. L., & Caughlin, J. P. (1997). Revealing family secrets: The influence of topic, function, and relationships. *Journal of Social and Personal Relationships, 14*(5), 679-705.

Vig, E. K., Starks, H., Taylor, J. S., Hopley, E. K., & Fryer-Edwards, K. (2007). Surviving surrogate decision-making: what helps and hampers the experience of making medical decisions for others. *Journal of General Internal Medicine, 22*(9), 1274-1279.

Vig, E. K., Taylor, J. S., Starks, H., Hopley, E. K., & Fryer-Edwards, K. (2006). Beyond Substituted Judgment: How Surrogates Navigate End-of-Life Decision-Making. *Journal of the American Geriatrics Society, 54*(11), 1688-1693.

Virdun, C., Luckett, T., Lorenz, K., Davidson, P. M., & Phillips, J. (2016). Dying in the hospital setting: A meta-synthesis identifying the elements of end-of-life care that patients and their families describe as being important. *Palliative Medicine*, 0269216316673547.

Wallace, C. L. (2015). Family communication and decision making at the end of life: a literature review. *Palliative and Supportive Care, 13*(03), 815-825.

Waller, A., Hall, A., Sanson-Fisher, R., Zdenkowski, N., Douglas, C., & Walsh, J. (2018). Do medical oncology patients and their support persons agree about end-of-life issues? *Internal Medicine Journal*, *48*(1), 60-66.

Wittenberg-Lyles, E., Goldsmith, J., Demiris, G., Oliver, D. P., & Stone, J. (2012). The impact of family communication patterns on hospice family caregivers: A new typology. *Journal of Hospice and Palliative Nursing*, *14*(1), 25.

Xu, S., & Lorber, M. F. (2014). Interrater agreement statistics with skewed data: Evaluation of alternatives to Cohen's kappa. *Journal Of Consulting And Clinical Psychology*, 82(6), 1219-12

APPENDIX A

PATIENT SURVEY FOR STUDY ONE

The purpose of this research project is to investigate the way patients and their surrogate decision makers communicate and think about medical decisions for end-of-life care. To participate in this survey, you must be over 65 and willing to provide the first name and e-mail address of the person who will most likely make medical decisions for your end-of-life care.

We will call this person your surrogate decision-maker because they will be the person who will most likely make decisions for you when you are no longer able to do so. We will email your surrogate decision-maker a separate survey. In order to use your survey responses as part of our research project, your surrogate decision-maker must also complete their survey.

1. List the first name and email address of the person you expect to be your surrogate decision-maker for you when are at the end of your life. This is the person who would have the ultimate say in your end-of-life care treatment when you are unable to make decisions for yourself.

[name provided here will be used in subsequent questions]

2. What is this person's relationship to you?

A. Spouse or romantic partner
B. Child or Stepchild
C. Brother or Sister, Stepbrother or stepsister
D. Niece or nephew
E. Other family member
F. Friend
G. Other: _____

3. When we email your surrogate decision-maker their survey, we will let them know who referred them to our project in order to avoid confusion. Our message will say "__(your first name)_____ has participated in our research project and listed you as someone who would likely be his or her surrogate decision-maker for healthcare decisions." Please provide your first name below so that we can include it in our email to your surrogate decision-maker.

INSTRUCTIONS: In this scale, we are interested in your relationship with [[your surrogate decision-maker]][[will use piped text to indicate surrogate's name throughout survey, rather than use the term "surrogate decision-maker"]].

Answer the questions according to how much you agree with the statement. The responses range from 1 (strongly disagree) to 5 (strongly agree).

4. My relationship with my surrogate is close.
5. My surrogate and I disclose important personal things to each other.
6. My surrogate and I have a strong connection.
7. My surrogate and I do a lot of things together.
8. I consider my surrogate when making important decisions.

9. Describe your current health status.

A. Excellent
B. Very good
C. Good
D. Poor
E. Very poor

10. Have you discussed your end-of-life care wishes with your surrogate decision maker [text-fill name]?

A. Yes
B. No

11. Have you recorded your end-of-life care wishes in a document, on a video, or in an audio recording?

A. Yes
B. No

12. Have you discussed your end-of-life care wishes with your physician?

A. Yes
B. No

SKIP LOGIC: If yes to question 10 or yes to question 11, answer questions 13-15. If not, answer questions 16-21.

INSTRUCTIONS: In this scale, we are interested in YOUR reasons for choosing to express your end-of-life care wishes to others.

Answer the questions according to how much you agree with the statement. The responses range from 1 (strongly disagree) to 5 (strongly agree).

13. I want to be able to make my own decisions.

14. There may be differences of opinion about my care among my family members.

15. I hope not to burden my family with making treatment decisions for me.

INSTRUCTIONS: In this scale, we are interested in YOUR reasons for not or choosing to express your end-of-life care wishes to others.

Answer the questions according to how much you agree with the statement. The responses range from 1 (strongly disagree) to 5 (strongly agree).

16. I am currently healthy and there is no need to think about illness and death.

17. I will take it as it comes because I have no control over my death.

18. I cannot imagine my end-of-life care.

19. I do not want to think that I will eventually die or lose my memory.

20. I felt that it was best to leave my future to fate or a higher power.

21. I believed that planning of my death would mean that there is no hope for me.

INSTRUCTIONS: In this scale, we are interested in knowing how you and your immediate family members AS A WHOLE communicate with one another. Answer the questions according to how much you agree with the statement. The responses range from 1 (strongly disagree) to 7 (strongly agree).

22. In our family, we often talk about topics like politics and religion where some people disagree with others.
23. I often say something like "Every member of the family should have some say in family decisions."
24. Parents should ask a child's opinion when the family is talking about something.
25. Parents should encourage children to challenge my ideas and beliefs.
26. Children should tell a parent what he or she is thinking about things.
27. Children should tell his or her parents almost anything.
28. In our family we often talk about our feelings and emotions.
29. My family and I often have relaxed conversations about nothing in particular.
30. In our family, we often talk about our plans and hopes for the future.
31. I often say things like "My ideas are right and you should not question them."
32. I often say things like "A child should not argue with adults."
33. I often say things like "There are some things that just shouldn't be talked about."
34. I often say something like "You should give in on arguments rather than risk making people mad."
35. When anything really important is involved, a child should be expected to obey his or her parent without question.
36. If I don't approve of it, I don't want to know about it.
37. My family has had regular family dinners together.
38. Family members are encouraged to engage in fun activities such as movies or vacations together.
39. Family members are expected to be honest with one another.

40. In my home, the family follows traditions (such as praying before meals and household chores).
41. I expect to spend time with my family during evenings and weekends.
42. Family members are encouraged to have strong emotional attachments to other family members.

INSTRUCTIONS: In this scale, we are interested in knowing how you and your PRIMARY SURROGATE DECISION-MAKER [[Use text flow to fill in person's first name.]](the person you named in question 4) communicate with one another.

Answer the questions according to how much you agree with the statement. The responses range from 1 (strongly disagree) to 5 (strongly agree).

58. I am mostly the one who starts conversations with my surrogate decision-maker about death and dying.
59. I do not often talk about death and dying with my surrogate decision-maker.
60. My conversations with my surrogate decision-maker and dying are usually brief.
61. Talking about emotions related to death and dying upsets my surrogate decision-maker.
62. Talking about what happens physically during death and dying upsets my surrogate decision-maker.
63. Talking about potential pain and suffering related to death and dying upsets my surrogate decision-maker.
64. Talking about spiritual questions related to death and dying upsets my surrogate decision-maker.

INSTRUCTIONS: In this scale, we are interested in knowing YOUR current goals for your end-of-life care. For each item, choose the answer that best reflects your end-of-life care goals.

Answer each question according to how important the described characteristic is to making end-of-life care decisions that affect your quality of life. The responses range from 1 (not at all important) to 5 (extremely important).

In order to enjoy living, it is _____ important for me to be able to:

65. Enjoy everyday experiences, such as listening to music, watching television, and having conversations.
66. Eat food on my own.
67. Know I am not a burden on family.
68. Receive end-of-life care at home.
69. Be free from pain.

In this section, you will answer questions about your own end-of-life care goals and how you think surrogate decision makers should make decisions.

INSTRUCTIONS: In this scale, we are interested in knowing YOUR beliefs about surrogate decision-making.

Answer each question according to how important the described characteristic is for a surrogate to do when making end-of-life care decisions. The responses range from 1 (not at all important) to 5 (extremely important).

When making decisions on behalf of a patient, a surrogate healthcare decision-maker should

70. Make decisions on behalf of a patient based on the conversations the two have had.
71. Rely most on the patient's preferences expressed in legal documents.
72. Rely on their inner sense of what the patient would want.
73. Rely on their own values and sense of what's right.
74. Get help from others, such as friends and family, who might know the patient's goals.

INSTRUCTIONS: In this scale, we are interested in knowing how you feel about your ability to communicate with YOUR SURROGATE DECISION-MAKER [[Use text flow to fill in person's first name.]] and your physician about your end-of-life care goals.

Answer the questions according to how much you agree with the statement. The responses range from 1 (strongly disagree) to 5 (strongly agree).

I am confident in my ability to:

75. Initiate a conversation with my surrogate decision-maker about my end-of-life care goals.
76. Express my end-of-life care goals to my surrogate decision-maker.
77. Talk about emotions related to my end-of-life care with my surrogate decision-maker.
78. Talk about what will happen to my body during my end-of-life care my surrogate decision-maker.
79. Talk about spiritual questions related to death and dying with my surrogate decision-maker.
80. Talk with my physician about my who surrogate decision-maker is and what my end-of-life care goals are.

In this section, you will answer questions about what you think your surrogate decision-makers thinks you want. In other words, how would he/she guess you would answer the questions. PLEASE DO NOT ASK YOUR SURROGATE FOR THEIR ANSWERS BEFORE COMPLETING THIS SECTION.

INSTRUCTIONS: In this scale, we are interested in knowing what YOUR SURROGATE THINKS YOUR end-of-life care preferences are. For each item, choose the answer that best reflects YOUR SURROGATE's INTERPRETATION of your wishes based on the description provided.

Answer each question according to how important the described characteristic is to making end-of-life care decisions that affect your quality of life. The responses range from 1 (not at all important) to 5 (extremely important).

If you asked my surrogate, he or she would say that in order to enjoy my life, I believe it is _____ important to have the ability to:

81. Enjoy everyday experiences, such as listening to music, watching television, and having conversations.
82. Eat food on my own.
83. Know I am not a burden on family.
84. Receive end-of-life care at home.
85. Be free from pain.

INSTRUCTIONS: In this scale, we are interested in knowing what YOU think is most important for your surrogate decision-maker to discuss with your physician.

If your surrogate decision-maker were to have a conversation with your physician about your end-of-life care, which are the top three issues you would want him or her to consider? Start by placing the number 1 by the most important issue and continue through the number 3.

86. How much a treatment would cost.
87. How long I would have to be hospitalized.
88. How likely a treatment would relieve symptoms.
89. How risky a treatment would be to my life.
90. How painful a treatment would be.
91. How life-limiting the side-effects would be.

INSTRUCTIONS: Please answer the following demographic questions about yourself to the best of your ability.

77. What is your age in years? _____

78. What is your sex?

A. Male
B. Female
C. Neither

79. What is your ethnicity? (Choose all that apply)

A. Caucasian
B. Black / African American
C. Asian / Pacific Islander
D. Native American

E. Hispanic
F. Middle Eastern
G. Other _____
H. Prefer not to answer

80. What is your annual household income?

Less than $24,999
$25,000 to $49,999
$50,000 to 99,999
$100,000 or more

81. Approximately how far away from one another do you and your surrogate decision-maker live?

Less than 10 miles.
Between 10 and 50 miles.
Between 51 and 200 miles.
Over 200 miles.

APPENDIX B

SURROGATE SURVEY FOR STUDY ONE

The purpose of this research project is to investigate the way patients and their surrogate decision makers communicate and think about medical decisions for end-of-life care. You were referred to take this survey because _____ believes you will likely be his or her surrogate decision maker for end-of-life care.

A surrogate decision-maker is the person who will most likely make decisions when _____ is no longer able to do so. In order to use _____'s survey responses as part of our research project, you must complete this survey so that we also have your responses.

1. List the first name and email address of the person who referred you to this study. This should be the person for whom you expect to be the primary healthcare decision-maker (called surrogate decision-maker) at the end of life. You would be the person who would have the ultimate say in the patient's end-of-life care treatment when they are unable to make decisions for themselves.

[name provided here will be used in subsequent questions]

2. What is this person's relationship to you?

H. Spouse or romantic partner
I. Child or Stepchild
J. Brother or Sister, Stepbrother or stepsister
K. Niece or nephew
L. Other family member
M. Friend
N. Other: _____

INSTRUCTIONS: In this scale, we are interested in your relationship with [[the patient]][[will use piped text to indicate patient's name throughout survey, rather than use the term "patient"]].

Answer the questions according to how much you agree with the statement. The responses range from 1 (strongly disagree) to 5 (strongly agree).

3. My relationship with the patient is close.
4. The patient and I disclose important personal things to each other.
5. The patient and I have a strong connection.
6. The patient and I do a lot of things together.

7. I consider the patient when making important decisions.

8. Have you discussed the patient's **[[Use text flow to fill in patient's first name.]]** end-of-life care wishes with them?

A. Yes
B. No

9. Has the patient recorded his or her end-of-life care wishes in a document, on a video, or in an audio recording?

A. Yes
B. No

10. Have the patient discussed his or her end-of-life care wishes with his or her physician?

A. Yes
B. No
C. Don't know

SKIP LOGIC: If yes to question 8 or yes to question 9, answer questions 11-13. If not, answer questions 14-19.

INSTRUCTIONS: In this scale, we are interested in THE PATIENT'S reasons for expressing their end-of-life care wishes.

Answer the questions according to how much you think THE PATIENT AGREES with the statement. The responses range from 1 (strongly disagree) to 5 (strongly agree).

The patient would _____ with this statement:

11. I want to be able to make my own decisions.

12. There may be differences of opinion about my care among my family members.

13. I hope not to burden my family with making treatment decisions for me.

INSTRUCTIONS: In this scale, we are interested in THE PATIENT'S reasons for not expressing their end-of-life care wishes.

Answer the questions according to how much you think THE PATIENT AGREES with the statement. The responses range from 1 (strongly disagree) to 5 (strongly agree).

The patient would _____ with this statement:

14. I am currently healthy and there is no need to think about illness and death.

15. I will take it as it comes because I have no control over my death.

16. I cannot imagine my end-of-life care.

17. I do not want to think that I will eventually die or lose my memory.

18. I felt that it was best to leave my future to fate or a higher power.

19. I believed that planning of my death would mean that there is no hope for me.

INSTRUCTIONS: In this scale, we are interested in knowing how you and your immediate family members AS A WHOLE communicate with one another. Answer the questions according to how much you agree with the statement. The responses range from 1 (strongly disagree) to 7 (strongly agree).

20. In our family, we often talk about topics like politics and religion where some people disagree with others.
21. I often say something like "Every member of the family should have some say in family decisions."
22. Parents should ask a child's opinion when the family is talking about something.
23. Parents should encourage children to challenge my ideas and beliefs.
24. Children should tell a parent what he or she is thinking about things.
25. Children should tell his or her parents almost anything.
26. In our family we often talk about our feelings and emotions.
27. My family and I often have relaxed conversations about nothing in particular.
28. In our family, we often talk about our plans and hopes for the future.
29. I often say things like "My ideas are right and you should not question them."
30. I often say things like "A child should not argue with adults."
31. I often say things like "There are some things that just shouldn't be talked about."
32. I often say something like "You should give in on arguments rather than risk making people mad."
33. When anything really important is involved, a child should be expected to obey his or her parent without question.
34. If I don't approve of it, I don't want to know about it.
35. My family has had regular family dinners together.
36. Family members are encouraged to engage in fun activities such as movies or vacations together.
37. Family members are expected to be honest with one another.
38. In my home, the family follows traditions (such as praying before meals and household chores).
39. I expect to spend time with my family during evenings and weekends.
40. Family members are encouraged to have strong emotional attachments to other family members.

INSTRUCTIONS: In this scale, we are interested in knowing how you and THE PATIENT [[Use text flow to fill in person's first name.]](the person you named in question 4) communicate with one another.

Answer the questions according to how much you agree with the statement. The responses range from 1 (strongly disagree) to 5 (strongly agree).

41. I am mostly the one who starts conversations with the patient about death and dying.
42. I do not often talk about death and dying with the patient.
43. My conversations with the patient about death and dying are usually brief.
44. Talking about emotions related to death and dying upsets the patient.
45. Talking about what happens physically during death and dying upsets the patient.
46. Talking about potential pain and suffering related to death and dying upsets the patient.
47. Talking about spiritual questions related to death and dying upsets the patient.

In this section, you will answer questions about your end-of-life care goals and how you think surrogate decision makers should make decisions.

INSTRUCTIONS: In this scale, we are interested in knowing YOUR current goals for your end-of-life care. For each item, choose the answer that best reflects your end-of-life care goals.

Answer each question according to how important the described characteristic is to making end-of-life care decisions that affect your quality of life. The responses range from 1 (not at all important) to 5 (extremely important).

In order to enjoy living, it is _____ important for me to be able to:

48. Enjoy everyday experiences, such as listening to music, watching television, and having conversations.
49. Eat food on my own.
50. Know I am not a burden on family.
51. Receive end-of-life care at home.
52. Be free from pain.

In this section, you will answer questions about your own end-of-life care goals and how you think surrogate decision makers should make decisions.

INSTRUCTIONS: In this scale, we are interested in knowing YOUR beliefs about surrogate decision-making.

Answer each question according to how important the described characteristic is for a surrogate to do when making end-of-life care decisions. The responses range from 1 (not at all important) to 5 (extremely important).

When making decisions on behalf of a patient, a surrogate healthcare decision-maker should

53. Make decisions on behalf of a patient based on the conversations the two have had.

54. Rely most on the patient's preferences expressed in legal documents.
55. Rely on their inner sense of what the patient would want.
56. Rely on their own values and sense of what's right.
57. Get help from others, such as friends and family, who might know the patient's goals.

INSTRUCTIONS: In this scale, we are interested in knowing how you feel about your ability to communicate with YOUR SURROGATE DECISION-MAKER [[Use text flow to fill in person's first name.]] and your physician about your end-of-life care goals.

Answer the questions according to how much you agree with the statement. The responses range from 1 (strongly disagree) to 5 (strongly agree).

I am confident in my ability to:

58. Initiate a conversation with my surrogate decision-maker about my end-of-life care goals.
59. Express my end-of-life care goals to my surrogate decision-maker.
60. Talk about emotions related to my end-of-life care with my surrogate decision-maker.
61. Talk about what will happen to my body during my end-of-life care my surrogate decision-maker.
62. Talk about spiritual questions related to death and dying with my surrogate decision-maker.
63. Talk with my physician about my who surrogate decision-maker is and what my end-of-life care goals are.

In this section, you will answer questions about what THE PATIENT wants. These questions are the same ones you answered about yourself, but this time, we want you think about what the patient wants, which might be the same or might be different from your own goals and beliefs. PLEASE DO NOT ASK THE PATIENT FOR THEIR ANSWERS BEFORE COMPLETING THIS SECTION.

INSTRUCTIONS: In this scale, we are interested in knowing what you think THE PATIENT's current end-of-life care preferences are. For each item, choose the answer that best reflects your end-of-life care goals.

The responses range from 1 (not at all important) to 5 (extremely important).

The patient would say, "In order to enjoy living, it is _____ important for me to be able to:

64. Enjoy everyday experiences, such as listening to music, watching television, and having conversations.
65. Eat food on my own.
66. Know I am not a burden on family.
67. Receive end-of-life care at home.
68. Be free from pain.

INSTRUCTIONS: In this scale, we are interested in knowing what THE PATIENT thinks is most important for you to discuss with his or her physician.

If your surrogate decision-maker were to have a conversation with your physician about your end-of-life care, which are the top three issues you would want him or her to consider? Start by placing the number 1 by the most important issue and continue through the number 3.

69. How much a treatment would cost.
70. How long I would have to be hospitalized.
71. How likely a treatment would relieve symptoms.
72. How risky a treatment would be to my life.
73. How painful a treatment would be.
74. How life-limiting the side-effects would be.

Demographic Data

INSTRUCTIONS: Please answer the following demographic questions about yourself to the best of your ability.

75. What is your age in years? _____

76. What is your sex?

A. Male
B. Female
C. Neither

77. What is your ethnicity? (Choose all that apply)

A. Caucasian
B. Black / African American
C. Asian / Pacific Islander
D. Native American
E. Hispanic
F. Middle Eastern
G. Other _____
H. Prefer not to answer

78. What is your annual household income?

Less than $24,999
$25,000 to $49,999
$50,000 to 99,999
$100,000 or more

79. How many children under the age of 18 currently live in your household?

0
1
2
3
4 or more

80. Approximately how far away from one another do you and the patient live?

Less than 10 miles.
Between 10 and 50 miles.
Between 51 and 200 miles.
Over 200 miles.

APPENDIX C

DESCRIPTIVE STATISTICS FOR STUDY ONE INDEPENDENT VARIABLES

Variable	Patient Mean (Standard Deviation) n=79	Surrogate Mean (Standard Deviation) n=79
Health Status	3.6 (1.1)	N/A
Closeness	22.2 (3.5)	23.4 (4.0)
Openness	22.1 (6.1)	22.2 (6.9)
Self-Efficacy	25.6 (4.0)	26.3 (3.2)
Family Communication Patterns		
Conversation Orientation	48.1 (9.1)	49.8 (7.6)
Conformity Orientation	21.6 (11.3)	22.2 (10.8)
Warm Conformity	33.2 (5.7)	33.9 (6.4)

APPENDIX D

FACTOR ANALYSIS FOR SHORTENED FAMILY COMMUNICATION PATTERNS MEASURES

In a previous project, respondent who identified as grandparents (ages 45 to 88, n=189) were asked to complete the Family Communication Patterns measure as part of an online survey. The original measure has a total of 26 questions, 15 assessing conversation orientation, and 11 assessing conformity orientation (Koerner & Fitzpatrick, 2002a). In an effort to reduce respondent burden, confirmatory and exploratory factor analyses were conducted using principal component analysis with Varimax rotation in SPSS.

The factor loadings and communalities for the conversation orientation scale and the conformity orientation scale are shown in the table below. Based on these results, the conversation orientation scale was reduced to 9 items, and the conformity orientation scale was reduced to 6 items. The reliabilities for the short-form scales were calculated and are also shown in the table below.

Item (Retained items in bold)	Factor Loading	Communality
Conversation Orientation (α=.889)		
In our family, we often talk about topics like politics and religion where some persons disagree with others.	**.485**	**.238**
I often say something like "Every member of the family should have some say in family decisions."	**.600**	**.366**

I often ask my opinion when the family is talking about something.	**.784**	**.614**
I encourage my children to challenge their ideas and beliefs.	**.692**	**.480**
I often say something like, "You should always look at both sides of an issue."	.683	.468
I usually tell my children what I am thinking about things.	**.749**	**.562**
I can tell my children almost anything.	**.801**	**.645**
In our family we often talk about our feelings and emotions.	**.718**	**.517**
My children and I often have long, relaxed conversations about nothing in particular.	**.800**	**.641**
I really enjoy talking with my parents, even when we disagree.	.734	.551
I like to hear opinions from my children, even when they don't agree with me.	.822	.679
I encourage my children to express their feelings.	.841	.707
I tend to be very open about my emotions with my children.	.618	.383
We often talk as a family about things we have done during the day.	.699	.512
In our family, we often talk about our plans and hopes for the future.	**.780**	**.612**
Conformity Orientation (α=.870)		
I often say something like "You'll know better when you grow up."	.493	.281
I often say something like "My ideas are right and you should not question them."	**.702**	**.532**
I often say something like "A child should not argue with adults."	**.777**	**.610**
I often say something like "There are some things that just shouldn't be talked about."	**.744**	**.575**
I often say something like "You should give in on arguments rather than risk making people mad."	**.672**	**.460**
When anything really important is involved, I expect my children to obey without question.	**.796**	**.633**
In our home, parents usually have the last word.	.753	.577

I feel that it is important to be the boss.	.668	.479
I sometimes become irritated with my children's views if they are different from mine.	.643	.417
If I don't approve of it, they don't want to know about it.	**.618**	**.419**
When my children are at home, they are expected to obey the parents' rules.	.577	.423

APPENDIX E

INDIVIDUAL RESPONSE QUESTIONS AND JOINT CONVERSATION GUIDE FOR STUDY TWO

Introduction to study:

I am first giving you your own digital recorder. I have pressed the record button for you already.

I am also giving you four small sheets of paper. On the first sheet you will find questions about you and your family. Please start by reading the first question into the recorder and then saying your answer. Continue by reading and then answering each additional question on the sheet until you have read and answered every question on the sheet. Your answers to some of these questions need not be long, but sufficient to help me understand you and your family members' circumstances.

On each subsequent sheet of paper is a small part of a hypothetical scenario. The scenario involves a common situation in end-of-life care: the placement of a feeding tube. Please read the short description of the scenario into your recorder and then read and answer the questions that follow. These instructions are repeated on each sheet. These recordings will only be heard by members of the research team who will not know your identity, so your responses will be kept anonymous. I will not share Patient's (P's) responses with Surrogate (S) or S's responses with P, but I will ask you to talk generally about some of the ideas in the questions. You may choose to share as much or as little of your responses as you wish.

Once you have finished making your recording, please return to where I am sitting. I will ask both of you to talk to me about your family and advance care planning. Again, you are not required to share anything in your individual recording you do not wish to, but I will ask you to discuss with one another some of the ideas related to decision-making included in the questions.

I would now like for each of you, P and S to take your recorder into a quiet and private space and begin.

INDIVIDUAL QUESTIONS FOR SURROGATES

PAGE ONE: GATHERING INFORMATION ABOUT FAMILY

Please read each question into the recorder and say your answer.

How does P usually make important health decisions?

What are P's goals, desires, and wishes with regard to their end-of-life care?

Is there anyone else in your family who should or would want to be involved in any healthcare health care decisions made for P?

Who among these people would be most helpful in making decisions for P?

Who among these people best understands P's goals, desires, and wishes?

Who among these people would be least helpful in making decisions for P?

Who among these people least understands P's goals, desires, and wishes?

PAGE TWO: DECIDING ON THE FEEDING TUBE

Please read the following scenario into your recorder. When you finish, read each question into the recorder and say your answer.

P has become very ill because of an underlying condition and can no longer feed him/herself. P's physician has explained that a feeding tube can be inserted through the skin so that P can receive nutrition without having to eat food. The physician has explained some of the benefits and risks of the feeding tube. The main benefit of the feeding tube is that it will help P maintain a healthy weight, which will help P live longer. The main risks include the added stress of a surgical procedure to insert the tube and the possibility of infection. P's feeding tube will require daily monitoring, and once it is inserted, P can no longer have any food by mouth.

Please read each of the following questions and say your answer.

What additional information do you feel you need to make this decision?

How do you feel about making this decision?

What would P want you to do?

Which family members would you turn to discuss this decision? Why have you chosen these people?

Who among your family members might have issues, objections, or otherwise question this decision?

What would you do to help resolve any disagreements about this decision?

PAGE THREE: A FEEDING TUBE COMPLICATION

Please read the following scenario into your recorder. When you finish, read each question into the recorder and say your answer.

You and P's physician ultimately decided on the feeding tube. But P has become very ill with nausea and diarrhea following placement of the feeding tube. P's physicians aren't sure of the cause, but they believe these symptoms might have been caused by the type of feeding tube that P was given. P's physicians have offered two choices: a new type of feeding tube can be inserted during a similar procedure, or the current feeding tube can be removed completely, and P can be fed carefully by hand. The main benefit of inserting a new kind of feeding tube is that it will help P maintain a healthy weight, which will help P live longer. The main risks include the added stress of another surgical procedure and the possibility of infection. Removing the tube and switching to hand feeding will help P avoid the risks of the new procedure and allow P to enjoy meals again. However, hand feeding will require family and nursing staff to constantly monitor P, and P will have trouble getting enough nutrition to maintain his or her weight.

Please read each of the following questions and say your answer.

What additional information do you feel you need to make this decision?

How do you feel about making this decision?

What would P want you to do?

Which family members would you turn to discuss this decision? Why have you chosen these people?

Who among your family members might have issues, objections, or otherwise question this decision?

What would you do to help resolve any disagreements about this decision?

INDIVIDUAL QUESTIONS FOR PATIENTS

PAGE ONE: GATHERING INFORMATION ABOUT FAMILY

Please read each question into the recorder and say your answer.

How do you usually make important health decisions?

What are your goals, desires, and wishes with regard to their end-of-life care?

Is there anyone else in your family who should or would want to be involved in any healthcare health care decisions made for you?

Who among these people would be most helpful in making decisions for you?

Who among these people best understands your goals, desires, and wishes?

Who among these people would be least helpful in making decisions for you?

Who among these people least understands your goals, desires, and wishes?

PAGE TWO: DECIDING ON THE FEEDING TUBE

Please read the following scenario into your recorder. When you finish, read each question into the recorder and say your answer.

You have become very ill because of an underlying condition and can no longer feed yourself or make decisions for yourself. Your physician has explained that a feeding tube can be inserted through the skin so that you can receive nutrition without having to eat food. The physician has explained some of the benefits and risks of the feeding tube. The main benefit of the feeding tube is that it will help you maintain a healthy weight, which will help you live longer. The main risks include the added stress of a surgical procedure to insert the tube and the possibility of infection. Your feeding tube will require daily monitoring, and once it is inserted, you can no longer have any food by mouth.

Please read each of the following questions and say your answer.

What additional information do you feel S needs to make this decision?

How do you feel about S making this decision?

What would you want S to do?

Which family members would S turn to discuss this decision? Why would S choose these people?

Who among your family members might have issues, objections, or otherwise question this decision?

What would S do to help resolve any disagreements about this decision?

PAGE THREE: A FEEDING TUBE COMPLICATION

Please read the following scenario into your recorder. When you finish, read each question into the recorder and say your answer.

S and your physicians decided to insert the feeding tube. You have become very ill with nausea and diarrhea following placement of the feeding tube. Your physicians aren't sure of the cause, but they believe these symptoms might have been caused by the type of feeding tube you were given. Your physicians have offered S two choices: a new type of feeding tube can be inserted during a similar procedure, or the current feeding tube can be removed completely, and you can be fed carefully by hand. The main benefit of inserting a new kind of feeding tube is that it will help you maintain a healthy weight, which will help you live longer. The main risks include the added stress of another surgical procedure and the possibility of infection. Removing the tube and switching to hand feeding will help you avoid the risks of the new procedure and allow you to enjoy meals again. However, hand feeding will require family and nursing staff to constantly monitor you, and you will have trouble getting enough nutrition to maintain your weight.

Please read each of the following questions and say your answer.

What additional information do you feel S needs to make this decision?

How do you feel about S making this decision?

What would you want S to do?

Which family members would S turn to discuss this decision? Why would S choose these people?

Who among your family members might have issues, objections, or otherwise question this decision?

What would S do to help resolve any disagreements about this decision?

DISCUSSION TOPICS AND QUESTIONS FOR PATIENT AND SURROGATE FOLLOW-UP

1. Confidence in knowing patient goals
    a. How confident do you each feel that you know and understand what P's (your own) goals and desires would be for his/her end-of-life care?
    b. How often have you discussed P's goals and desires would be for his/her end-of-life care?
    c. Do you feel like you have had productive conversations about P's goals and desires would be for his/her end-of-life care?
    d. What questions would you ask one another to help get clearer on goals and desires would be for his/her end-of-life care?
    e. Did the feeding tube scenario challenge your confidence in your knowledge of P's goals and desires at all?

2. Confidence in ability to convey goals to family and physicians.
    a. How confident do you each feel that that S can convey P's (your own) goals and desires would be for his/her end-of-life care to family members?
    b. How confident do you each feel that that S can convey P's (your own) goals and desires would be for his/her end-of-life care to physicians?
    c. What kinds of obstacles do you think might stand in the way of S conveying P's (your own) goals and desires would be for his/her end-of-life care to family members?
    d. What questions would you ask one another to help prepare S to convey P's goals and desires would be for his/her end-of-life care?
    e. Did the feeding tube scenario challenge your confidence in your S's ability to convey P's goals at all?

3. Confidence in carrying out care concordant with patient goals/wishes
    a. How confident do you each feel that S's goals and wishes will be carried out?
    b. What kinds of obstacles (institutional, personal, family, or otherwise) do you think might stand in the way of P receiving the care P wants?
    c. Do you have any concerns about dealing with these obstacles?
    d. Did the feeding tube scenario challenge your confidence in S's goals and wishes being carried out?

APPENDIX F

POST-CONVERSATION WRITING TASK

1. If you were to rate the openness of your conversation on a scale of 0 to 10, with 0 being poor and 10 being excellent, what rating would you give your conversation?

1 2 3 4 5 6 7 8 9 10

2. How do you feel after having this conversation?

3. Did you learn anything new about your conversation partner(s)? If so, what did you learn?

4. If you could continue this conversation, what would you want to talk about?

5. Please share any additional thoughts you have or feedback you have about participating in this conversation.

APPENDIX G

CODEBOOK FOR STUDY TWO

Code Type	Definition	Examples/Notes
Resistance Moves: Ways patients and surrogates avoided talking about death		
Can't Happen	Death is not going to happen to me.	• I'm too young • I'm too healthy • I'm not ready
Superstition	If we talk about death, it will happen, so I will not talk about it.	These instances used indirect, hushed language as if to say "shhh, death is listening." "Enough" was said twice.
Avoid indignities	Avoid talk about the indignities of dying by hastening death or "taking care of it."	Examples included suicide, homicide, and assisted suicide.

Code Type	Definition	Examples/Notes
Narratives: Stories related to uncertainties in advance care planning		
Characters	Major players in the story	Family members, "bad actors," fictional characters, famous people
Plot	Major events in the story	Death of someone, making a difficult decision, having conflict, going through hard financial times, grieving
Placement of story	Where story was located in the conversation	Story illustrates a point, provides "bad" example, bolsters family support (relational content), makes possible outcomes concrete, underscores disagreement.
Narrative purpose		
Cautionary Tale	Story about someone "getting it wrong"	Examples include bad relatives, unprepared people; focus was on judgment of the bad thing that happened or the bad person.
Social support	Telling family members "we're okay" because we're talking about this.	Stories were both positive and negative, but focus was on comparison to "us"
Projecting Outcomes	This terrible thing happened when these people didn't plan.	Focus was on the event, the actions that took place

Code Type	Definition	Examples/Notes
ACP Family Communication Environment		
ACP Problem Framing	How did the participants define advance care planning? What did they see as its role in end-of-life care? Was there urgency associated with advance care planning?	Looked for ways the participants made the problem concrete, as well as attitudes.
Attitudes Toward ACP	How did the participants feel about it?	Looked for resistance, fatalism, active stance, avoidance.
Conflict Style	How did participants talk about conflict with family?	Looked for strategies, attitudes, perceived threats.
Observed Behavior	How did the participants interact during the interview?	Looked for reliance on me as mediator, interaction with one another, rapport, turn-taking

APPENDIX H

CODEBOOK FOR STUDY THREE

Study Three Codes

Primary Code	Secondary Code	Definitions/Examples
Main Focus of Conversation	Documents	Focus on completing paperwork, adding to EMR, signatures, making it "official," updating records
	Surrogate decision maker	Focus on person or people, had to be more than facts such as name and phone number/address, had to include some detail about the patient/surrogate relationship
	Goals and preferences	Focus on what patient wants for their care, including concrete preferences and more ideals/goals/values for care
Discussion of Decision Making	Avoid having to make a difficult decision, help family avoid difficulty	Focus on "taking care" of the problem of end-of-life care by evoking suicide, homicide, assisted suicide
	Anticipating family burden because of the decision-making	Focus on family members' anguish, moral dilemmas associated with the patient's care; patient often wanted to spare family that anguish
	Avoid indignities associated with slow death	Focus on loss of independence, loss of autonomy and control
Narratives Dealing with Uncertainty	Justifying engagement in advance care planning	Cautionary tales, dilemmas of others

	Providing a basis for advance care planning choices	"I am not choosing my sister because she did…" "I don't want life-sustaining care because my friend did…"
	Grappling with the certainty of death and fear of death	"We're all going to die. My friend's mother died, and…" "We don't know what's on the other side…"
Language used to talk about death	Idioms	Indirect, polite references; includes sleep metaphors, which were common
	Biopolitical language	Mention of Schaivo, "my body," political language related to choice, self-governance
	Pop-culture and television references	Fictional characters, news stories
Conversational moves	Open-ended question	Question requiring and soliciting more than a yes/no answer
	Closed question	Yes/no, left/right, binary choice question.
	Validation	"Great job." "Wonderful." "Awesome."
	Blocking	Avoiding subject matter, changing the topic of conversation, refusing to answer a direct question